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From the Editor-in-Chief

This issue of *World Health & Population* presents papers that have been published online by *WHP* and are selected here as representative of recent outstanding contributions to the journal. The papers in this issue include two from China and one each from Bangladesh, Kenya and Kuwait.

The first article in this issue is "The Determinants of Early Cessation of Breastfeeding in Bangladesh," by Shamina Akter and Mizanur Rahman. The study uses data from the Bangladesh Demographic and Health Survey to explore the effect of parity and demographics on early cessation of breastfeeding, a known contributor to childhood mortality and morbidity, as well as a contributing cause for resumed fertility. Interestingly, the average duration of breastfeeding in Bangladesh, 27.5 months, is generally higher than that of other South Asian countries, which can be seen as a hopeful sign. The authors found continuance of breastfeeding, however, negatively associated with parity; that is, the higher the woman's parity, the more likely early cessation. Higher educational status was also associated with early cessation, which might indicate an appropriate group on which to focus the educational efforts recommended by the authors.

Community participation has been a recognized, if not always practised, part of international programs since the early 1980s and before. Both theory and experience (to say nothing about common sense) strongly support the idea of involving those we are trying to help in the design, implementation and evaluation of programs on their behalf. Unfortunately, efforts to involve the community have often fallen short. In "A Participatory Approach to Assessing Refugee Perceptions of Health Services," Brett Nelson, Marya Getchell, Stephanie Rosborough and colleagues propose and pilot an innovative method, called "by-person factor analysis" or Q-Methodology, for eliciting opinions and perceptions from an extremely disenfranchised community that of residents in refugee camps. It is also an encouraging sign that new methodologies are being developed for some of the most difficult settings. Certainly if they can be found to work in these settings, they can be adapted and applied elsewhere.

In the third article, Zhen Jiang, Debin Wang and colleagues examine the relationship between demographics, symptom severity and healthcare use in the article "Use of Health Services by Women with Gynecological Symptoms in Rural China." Utilizing a pre-tested cross-sectional survey of 1398 women (87.3% response rate), the authors found that approximately 70% had reported gynecological symptoms of varying seriousness during the last year. Of those reporting symptoms, slightly more than one-third reported seeking care. Educational level, not surprisingly, was strongly associated with seeking care and seeking it at higher-level facilities. Cost of care was clearly a factor as well. Given the importance of correct recognition of serious symptoms in reproductive health, the authors propose building a "grassroots capability" for proper health education of rural women and their healthcare providers.

Also examining health services in China, Qun Zhao, Xiaoming Li, Bonita Stanton et al. contend that the HIV/AIDS epidemic in China is still in its "early stages." This is certainly true when compared to Sub-Saharan Africa, which we hope China will never approach in terms of the extent of the infection and disease. Being in the early stages is also true, however, in terms of discussion of the disease and understanding of the relevant factors. Their article in this issue of *WHP*, "HIV/AIDS Awareness and Knowledge among Secondary School Students in China," begins filling in the knowledge gap with survey information from one of the most vulnerable populations – secondary school adolescents. The authors found low and inconsistent knowledge around HIV/AIDS, with males being more knowledgeable than females. Interestingly, the study also revealed that mass media

played a more significant role in information than parents, friends and peers, offering hope for public information campaigns to have an effect.

The final article in this issue is "Exploring the Meaning of Childhood Disability: Perceptions of Disability among Mothers of Children with Disabilities (CWD) in Kuwait." In this article, Sudha Raman, Shilpa Mandoda and colleagues report on results from Kuwait as part of their ongoing interest in perceptions of disability and health-seeking behaviours across countries and cultures. The authors point out that the concept of disability has ancient roots in societies but is changing greatly with advances in medical science, rehabilitation services and technology. Mothers, as the primary caregivers of CWDs, must often "hold in tension" traditional, fatalistic views of their child's disability, together with faith in the efficacy of the rehabilitation process. Understanding this tension can make designing programs more responsive and effective.

Finally, I would like to point out an editorial by Jennifer Zelmer, forthcoming in our companion Longwoods journal, *Healthcare Policy*. Professor Zelmer discusses the Millennium Development Goals (MDGs) in the context of reduction of infant mortality in Canada. It is important to remember that the achievement of the MDGs is challenged globally, not just confined to the most resource-constrained areas of the world.

In conclusion, we hope that you find the papers in this issue interesting and valuable, and that you will also consult others recently released online at www.worldhealthandpopulation.com. *WHP* remains committed to its mission to provide a forum for researchers and policy makers worldwide to publish and disseminate health- and population-related research, and to encourage applied research and policy analysis from diverse global settings. *WHP* is indexed on MEDLINE and is accessible through PubMed. We look forward to continued enthusiastic submission of manuscripts for consideration, peer review and publication. Finally, the editors and publishers of *WHP* are always interested in any comments or suggestions you might have on the papers or the journal. Please feel free to write or e-mail us.

John E. Paul, PhD
Editor-in-Chief, *World Health & Population*
paulj@email.unc.edu

The Determinants of Early Cessation of Breastfeeding in Bangladesh

Shamima Akter, PhD, Department of Population Science and Human Resource Development, University of Rajshahi, Rajshahi-6205, Bangladesh

Md. Mizanur Rahman, Assistant Professor, Department of Population Science and Human Resource Development, University of Rajshahi, Rajshahi-6205, Bangladesh

Correspondence may be directed to: Md. Mizanur Rahman, Assistant Professor, Department of Population Science and Human Resource Development, University of Rajshahi, Rajshahi-6205, Rajshahi, Bangladesh. E-mail: mizanur_rub@yahoo.com

Abstract

Early cessation of breastfeeding is a cause of significant concern in many developing countries. Premature discontinuation of breastfeeding is known to be associated with avoidable childhood morbidity and mortality as well as high levels of parity and avoidable pregnancies. Using a publicly available demographic dataset from Bangladesh, we applied a life table and Cox's proportional hazard model to investigate the duration and predictors of breastfeeding. The observed mean duration of breastfeeding was 27.5 months regardless of the level of parity. The results showed that age, age at the time of marriage, religion, the level of education of the mother, the geographic region of residence, employment status, parity and the use of contraceptives are important predictors of early cessation of breastfeeding.

Introduction

According to a World Health Organization report (WHO 1985), breastfeeding duration refers to the age of the child in months at the time of complete weaning, regardless of when consumption of other food began. Breastfeeding has been the subject of interest in developing countries because of its implications not only for the improved health of children, but also for lowering the fertility of the mothers (Abada et al. 2001; Sivakami 2003). Extended breastfeeding lengthens the period of reduced risk of conception and thus lengthens the interval between consecutive births, which in turn

indirectly reduces fertility (Huffman 1984; Thapa and Williamson 1990). Moreover, breastfeeding plays an important and influential role in child survival by providing immunological protection against early mortality. Age, education and socio-economic status of mothers are reported to be the main determinants of breastfeeding. Younger mothers are most likely to terminate breastfeeding earlier than older ones. Increased risk of early termination of breastfeeding has been associated with a higher level of education (Aryal 2007; Chaudhry et al. 2002). Empirical evidence indicates that rural women are more likely to breastfeed than urban women (Akin et al. 1981; Dow 1977; Jain and Bongaarts 1981; Kent 1981; Mohiuddin 1986; WHO 1985).

In Bangladesh, only 14% of infants are exclusively breastfed up to the age of 3 months (Haider et al. 1999). The study of the determinants of breastfeeding is important for the success of nutrition programs, which rely on the identification of factors susceptible to interventions. Although a number of studies have been carried out on breastfeeding patterns in Bangladesh, most of these studies have relied on old data and focused on one child (Ahmed et al. 1999; Giashuddin and Kabir 2003, 2004; Haider et al. 1999; Mannan and Islam 1995; Talukder 1992; Thapa and Williamson 1990). None of these studies attempted to relate the duration of breastfeeding to the level of parity, nor did they examine various demographic characteristics as potential determinants of breastfeeding. This study uses recent data and considers parity-specific breastfeeding patterns in an attempt to identify the predictors of the duration of breastfeeding.

Methods

Data and Sampling

Data for the present study were collected from Bangladesh Demographic and Health Survey (BDHS), which compiled information throughout the country from January to May 2004. BDHS (Mitra et al. 2005) employed a two-stage probability sample design to select respondents. The survey included 11,440 women between 10 and 49 years of age from 10,500 households covering 361 sample points. The sample points were composed of 122 urban and 239 rural areas that finally yielded 5,366 mothers who breastfed their children up to 36 months. Data for this study were analyzed using SPSS for Windows (Version 16.0), Statistica (Version 6.0) and Microsoft Excel.

Statistical Tools

Life-table and multivariate statistical techniques were employed to examine breastfeeding patterns. To determine factors affecting the duration of breastfeeding, we also used Cox's proportional hazard model (Cox 1972; Lawless 1982), which is a powerful tool for analyzing time-to-event data.

A life table was constructed by pooling completed and censored cases of breastfeeding (Lee 1993; Sivakami 2003). The completed cases were those in which breastfeeding had stopped and the exact duration of breastfeeding was known. The censored cases, on the other hand, were those in which the children were still being breastfed at the time of the survey. Using the following parameters, life tables were constructed from the month-wise probabilities of terminating breastfeeding.

N = Number of live births,

N_0 = Number of children ever breastfed,

d_i = Number of children for whom breastfeeding had stopped during the ith month since birth, for i = 1, 2, 3, ...,

c_i = Number of children who were being breastfed at the time of survey, with child in the ith month at the time of survey, for i = 1, 2, 3, ...,

w_i = Number of children who were breastfed until death in the ith month, for i = 1, 2, 3, ...,

Then, N_i = Number of children being breastfed at the end of the ith month since birth,

$= N_{i-1} - d_i - c_i - w_i$, for i = 1, 2, 3, …,

q_i = Probability of discontinuing breastfeeding during the ith month,

$$q_i = \frac{d_i}{N_{i-1} - 0.5(c_i + w_{i)}}, \text{ for } i = 1, 2, 3, \ldots, \text{ and}$$

P_i = Proportion of continuing breastfeeding at least up to the end of the ith month
= $(1 - q_i)\ P_i$ -1, for i = 1, 2, 3, ...,

Where
P_0 = Proportion ever breastfed = N_0 / N

A small adjustment to the above assumption was required when babies died immediately after birth, before breastfeeding could be initiated. If the number of such deaths is n; then P_0 is given by $N_0 / (N - n)$ instead of N_0 / N. From the computed values of P_i , the mean length of breastfeeding was obtained by the following standard life-table formula:

Mean length = $[½(P_i ,0 + P_i ,36) + 3(P_i ,1 + P_i , 2+ \ldots + P_i , 35)]$

Cox's Proportional Hazard Model

The net contribution of socio-demographic variables on cessation of breastfeeding was assessed by using Cox's proportional hazard model, which combines the features of life-table and regression (Cox 1972; Lawless 1982). The advantage of using such a multivariate model is that censored data resulting either from survival or death of the child are accommodated in the model. For this reason, the model has been shown to be appropriate for analysis of the duration of breastfeeding (Huffman et al. 1987). As such, the model is similar to regression analysis but is more useful in analyzing survival time, during which termination of breastfeeding can occur at any time. This model estimates the influences of a set of variables on the likelihood of terminating breastfeeding. The hazard function at time t (i.e., the time of termination of breastfeeding), denoted by $\lambda(t,z)$is expressed as

$$\lambda(t,z) = \lambda_0(t).\exp \sum X_i \beta_i$$

Where X_i is an explanatory variable, β_i is the regression coefficient and $\lambda_0(t)$ is the baseline hazard. The model assumes that independent variables exert an equal degree of hazard in each time interval (hence the term *proportional hazard*). The model is very useful in estimating the net effect of an independent factor on the likelihood of the termination of breastfeeding and the impact on other independent variables. The hazard ratio (odds ratio) for breastfeeding and its 95% confidence interval (CI) were calculated for the socio-demographic factors associated with breastfeeding. The independent variables used in the study include residence (urban vs. rural) region (six divisional cities), religion (Muslims vs. non-Muslims), education (illiterate, primary, secondary and higher), work status (does not work vs. works), mother's age (≤24, 25–34, ≥35 years), mother's age at marriage (≤14, 15–19, ≥25 years), parity (≤2, 3–5, ≥6) and use of contraceptives (never used vs. used) by the respondents.

Results and Discussion

Demographic Characteristics of the Study Population

The demographic profile of participants is given in Table 1. Of the 5366 participants, the vast majority (69%) lived in rural areas, whereas only 31% lived in urban areas. Altogether, 91% were Muslims and 9% were non-Muslims (Hindu, Christian and Buddhist). More than two thirds of participants had only a primary school education or none at all, and only 6% had been educated beyond the secondary school level. More than 80% were housewives, while less than 20% were gainfully employed. About one half of respondents were ≤24 years at the time of survey and had been married at the very early age of ≤14 years.

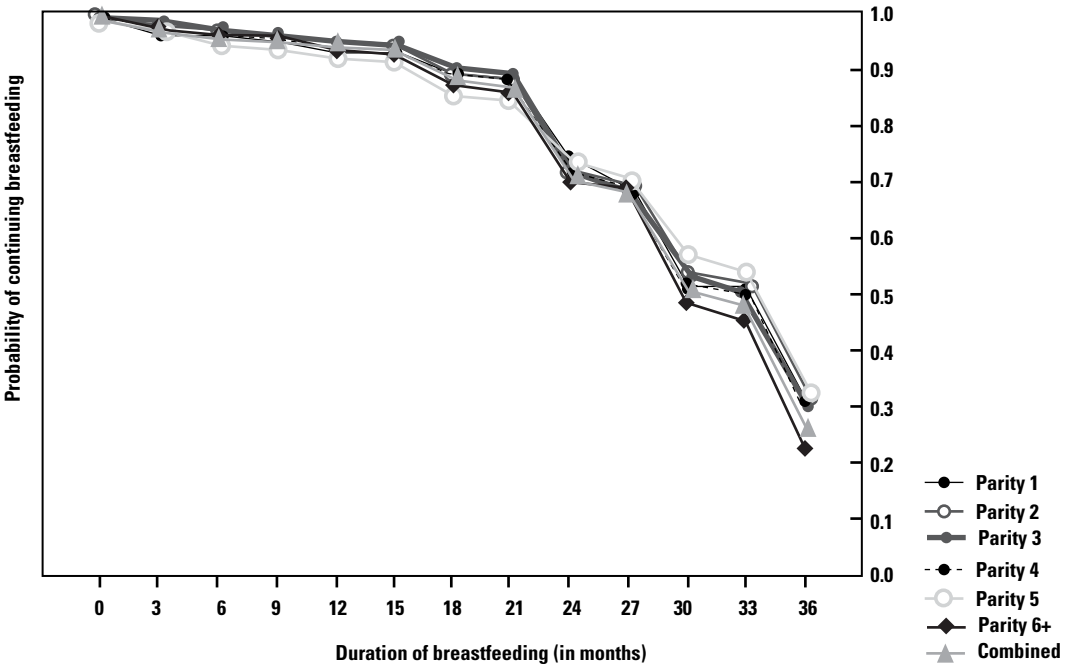
Table 1. Demographic characteristics of the study population (N = 5366)

Characteristics		Frequency (*N* = 5366)	%
Residence	Urban	1684	31.40
	Rural	3682	68.60
Region/Administrative division	Barisal	615	11.46
	Chittagong	1109	20.67
	Dhaka	1192	22.21
	Khulna	728	13.57
	Rajshahi	1085	20.22
	Sylhet	637	11.87
Religion	Muslim	4876	90.9
	Non-Muslim	490	9.13
Mother's education	No education	1866	34.77
	Primary	1649	30.73
	Secondary	1512	28.18
	Higher	339	6.32
Work status	Not working	4396	81.9
	Working	970	18.10
Respondent age (years)	≤24	2628	48.98
	25–34	2175	40.53
	35 and over	563	10.49
Age at marriage (years)	≤14	2695	50.22
	15–19	2301	42.88
	20–24	320	5.963
	25 and over	50	0.932
Parity of mothers	≤2	2876	53.60
	3–5	1928	35.93
	6 and over	562	10.47
Use of contraceptives	Never used	876	16.30
	Used	4490	83.70

Mean Duration of Breastfeeding

The mean duration of breastfeeding for Bangladeshi women under study was 27.5 months. Mitra et al. (2005) reported the average duration of breastfeeding to be 28.8 months, which is very close to our findings. Compared with Pakistan (Page et al. 1982), India (Rajaretnam 1994) and Sri Lanka (Mahler 1996), where the average duration of breastfeeding was 18.4, 21.8 and 23.2 months, respectively, the average duration of breastfeeding among Bangladeshi women seems considerably longer. In rural Guatemala the mean duration of breastfeeding, adjusted for different levels of parity, was found to be only 16.6 months (Aguirre and Jones 2005). In the present study the probability of breastfeeding is highest at 0 months (99%). This percentage decreases steadily as the time from birth increases (Figure 1). The probability of continuing breastfeeding declined substantially after 24 months.

Figure 1. Probability of continuing breastfeeding for specific durations, Bangladesh



Termination of Breastfeeding

Table 2 shows the hazard coefficients and relative risk of termination of breastfeeding for each covariate. All predictor variables except the place of residence were found to have significant influence on the decision to terminate breastfeeding. The region of residence had a significant impact on the probability of terminating breastfeeding. Whereas mothers from Chittagong were 1.1 times more likely to terminate breastfeeding earlier than those from Sylhet, mothers from the Barisal, Dhaka, Khulna and Rajshahi regions were considerably less likely to terminate breastfeeding earlier than those from Sylhet. Mannan and Islam (1995), Mitra et al. (1997) and Giashuddin and Kabir (2003, 2004) have previously reported similar results.

Table 2. Estimates of relative risk of cessation of breastfeeding in women in Bangladesh from January to May, 2004

Explanatory variables (X_i)	Coefficient (β)	Standard error of coefficient	P-values	Odds ratio	95% CI
Residence					
Urban	0.02	0.03	0.57	1.02	0.96–1.08
(Rural)	...	...		1.00	
Region					
Barisal	-0.10	0.06	0.08	0.90	0.80–1.01
Chittagong	0.10	0.05	0.05	1.11	1.00–1.22
Dhaka	-0.08	0.05	0.14	0.93	0.84–1.03
Khulna	-0.08	0.06	0.16	0.92	0.82–1.03
Rajshahi	-0.13	0.05	0.01	0.88	0.79–0.97
(Sylhet)	...	...	...	1.00	
Religion					
Muslim	0.21	0.05	0.00	1.23	1.12–1.36
(Non-Muslim)	...	...	...	1.00	
Educational level					
Illiterate	-0.27	0.07	0.00	0.76	0.67–0.87
Primary	-0.20	0.07	0.00	0.82	0.72–0.94
Secondary	-0.14	0.06	0.03	0.87	0.77–0.98
(Higher)	...	...	...	1.00	
Work Status					
Does not work	0.13	0.04	0.00	1.14	1.06–1.23
(Work)	...	...	...	1.00	
Mother's age (yrs)					
≤24	0.66	0.07	0.00	1.94	1.71–2.20
25–34	0.30	0.06	0.00	1.35	1.21–1.51
(≥35)	...	...	...	1.00	
Age at marriage					
≤14	-0.36	0.15	0.02	0.70	0.52–0.93
15–19	-0.31	0.15	0.04	0.73	0.55–0.98
20–24	-0.21	0.15	0.17	0.81	0.60–1.09
(≥25)	...	...		1.00	
Parity					
≤2	-0.36	0.07	0.00	0.70	0.61–0.79
3–5	-0.09	0.06	0.13	0.92	0.82–1.03
(≥6)	...	...		1.00	
Use of contraceptives					
Never used	0.31	0.04	0.00	1.37	1.26–1.48
(Used)	...	...	...	1.00	

CI = confidence interval.

Muslim mothers were 1.2 times more likely than their non-Muslim (Hindu, Christian and Buddhist) counterparts to terminate breastfeeding early. Non-Muslim mothers have previously been shown to breastfeed longer than Muslim mothers in other regions of the country as well (Giashuddin and Kabir 2003, 2004; Islam et al. 2006; Manna and Islam 1995). Education was found to have a significant negative impact on cessation of breastfeeding. Accordingly, the risk of early termination of breastfeeding for illiterate mothers and those with primary and secondary school education was 24%, 18% and 13%, respectively, lower than mothers with higher education. The association of higher education with shorter duration of breastfeeding was also noted in some earlier studies in Bangladesh (Giashuddin and Kabir 2003, 2004; Mannan and Islam 1995) and in other devel-

oping countries (Grummer-Strawn 1996). Notably, the situation in industrialized countries such as Denmark is quite the opposite (Vestermark et al. 1991).

Employment status outside the house was in general positively associated with the risk of terminating breastfeeding. The results indicate that women who do not work are 1.1 times more likely to terminate breastfeeding than working women. Previously, other studies have also shown that working women breastfeed longer than their non-working counterparts (Ahamed 1986; Mannan and Islam 1995; Sivakami 2003). The reason for this counter-intuitive observation might lie in the fact that most working women in Bangladesh take their babies with them to the workplace.

Maternal age was strongly associated with the risk of the termination of breastfeeding. Younger women (≤24 years and 25–34 years) had a significantly higher probability of terminating breastfeeding than those ≥35 years. These findings support the results of Mannan and Islam (1995) and Giashuddin and Kabir (2004), who showed that the risk of early weaning is lower among older mothers than younger ones.

Mothers' age at marriage also had a significantly negative correlation with the risk of early termination of breastfeeding. Women who were married at age ≤14, 15–19 and 20–24 years were 30%, 27% and 19%, respectively, less likely to terminate breastfeeding than those who were married at age ≥25 years. Parity also had a significantly negative effect on the duration of breastfeeding. Mothers with ≤2 and 3–5 parities were 30% and 8%, respectively, less likely to terminate breastfeeding than those with ≥6 parities. Not, surprisingly, the use of contraceptives was associated with a significantly lower risk of early cessation of breastfeeding.

Conclusion and Policy Implications

The duration of breastfeeding is an important topic in demographic research. The results of this study showed that breastfeeding is virtually universal and across the spectrum is prolonged in Bangladesh, averaging 27.5 months. The Cox proportional hazard model employed in this study identified correlates such as the region of residence, religion, maternal education, working status, maternal age, age at the time of marriage, parity and the use of contraceptives as significant determinants of the duration of breastfeeding among Bangladeshi women. In view of these findings, the following policy considerations are suggested. First, policy makers should institute health education programs to promote and facilitate optimal breastfeeding practices. Based on the findings of various studies, programs should be implemented to identify women who are highly susceptible to frequent pregnancies. Targeted programs in rural and urban areas should be developed to promote contraception measures and prolongation of breastfeeding when possible. Second, extensive media coverage of these issues should be promoted to highlight the benefits of breastfeeding in terms of improving child health and lowering susceptibility to pregnancy.

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A Participatory Approach to Assessing Refugee Perceptions of Health Services

Brett D. Nelson, MD, MPH, DTM&H, Department of Pediatrics and Division of Pediatric Global Health, Massachusetts General Hospital, Boston, Massachusetts, USA; Harvard Humanitarian Initiative, Harvard University, Cambridge, Massachusetts, USA

Marya Getchell, MSc, François-Xavier Bagnoud Center for Health and Human Rights, Harvard School of Public Health, Boston, Massachusetts, USA

Stephanie Rosborough, MD, MPH, Harvard Humanitarian Initiative, Harvard University, Cambridge, Massachusetts, USA; Department of Emergency Medicine, Brigham and Women's Hospital, Boston, Massachusetts, USA

Benjamin Atwine, MBChB, MPH, International Rescue Committee, Tanzania Program, Dar es Salaam, Tanzania

Elijah Okeyo, International Rescue Committee, Tanzania Program, Dar es Salaam, Tanzania

Earl Wall, MS, Center for Disaster and Refugee Studies, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland, USA

P. Gregg Greenough, MD, MPH, Harvard Humanitarian Initiative, Harvard University, Cambridge, Massachusetts, USA; Department of Emergency Medicine, Brigham and Women's Hospital, Boston, Massachusetts, USA

Correspondence may be directed to: Brett D. Nelson, MD, MPH, DTM&H, Massachusetts General Hospital: Division of Pediatric Global Health; Harvard Humanitarian Initiative: Co-director, Children in Conflict and Crisis; E-mail brett.d.nelson@gmail.com.

ABSTRACT

Objective: The necessity and value of beneficiary input is widely recognized by the humanitarian community. Nevertheless, limited beneficiary involvement occurs due to various barriers. This study explores the effectiveness of an innovative, participatory approach to assessing beneficiary perceptions in resource-limited settings.

Methods: A unique hybrid of qualitative and quantitative methodologies assessed perceptions of health programs within five refugee camps in Kenya and Tanzania. A database of perceptions and

opinions was established through key-informant interviews, focus group discussions and free-response questionnaires among refugees, community leaders and healthcare providers. Each participant subsequently force-ranked the collected views into quasi-normal distribution according to level of agreement. Responses were analyzed using by-person factor analysis software.

Findings: Eighty-one individuals (96%) successfully completed the participatory exercise. The methodologies identified detailed levels of consensus, rank-ordered priorities and unique sub-population opinions.

Conclusion: The authors illustrate benefits and feasibility of qualitative quantitative participatory methodology in assessing beneficiary perceptions of refugee services.

Introduction

The great importance and value of beneficiary input is widely accepted among the donor community and implementing agencies involved in humanitarian assistance. Taking into account beneficiary perceptions can allow programs to address the specific needs of aid recipients, improve community acceptance and foster sustainability (Bamberger 1988). However, limited beneficiary involvement often occurs due to a range of barriers, including cost, insufficient resources and the lack of established participatory methodology (Kaiser 2002). This paper explores the use of by-person factor analysis, or Q-methodology, as an innovative approach to collecting beneficiary perceptions of healthcare in resource-limited settings such as refugee camps. By-person factor analysis applied in refugee camps in Kenya and Tanzania, where health systems were well established, is used to illustrate the wealth of information that can be collected through this participatory method of assessment.

The Kakuma Refugee Camp located in northwestern Kenya was initially established in 1992 to accommodate refugees fleeing civil war in southern Sudan. In 2004, the total population of the camp was 90,441.

The Kakuma Refugee Camp located in northwestern Kenya was initially established in 1992 to accommodate refugees fleeing civil war in southern Sudan. In 2004, the total population of the camp was 90,441 and was comprised mainly of Sudanese (71%) and Somali (25%) refugees (International Rescue Committee 2004). A multinational camp, Kakuma is also home to refugees from several other countries such as Ethiopia, Burundi, Democratic Republic of Congo, Eritrea and Uganda.

The Kibondo District in western Tanzania contains four refugee camps: Kanembwa, Mkugwa, Mtendeli and Nduta. In 2005, these camps housed a total of 73,414 refugees. The shared border between Tanzania and Burundi results in a large concentration of Burundian refugees within the Kibondo District. Kanembwa was established in 1993, with Mtendeli and Nduta established the following year to accommodate the growing number of Burundian refugees fleeing political turmoil. The smallest camp, Mkugwa, was established in 1993 for Congolese and mixed ethnic groups such as intermarried Hutus and Tutsis.

An international humanitarian non-governmental organization (NGO) is responsible for preventive and curative health services within the Kakuma and Kibondo District refugee camps. Healthcare services provided in these refugee camps are quite comprehensive, ranging from immunization programs and family planning services to dental care and mental health. Quarterly program evaluations conducted by the implementing NGO through clinic reports and surveys provide quantitative data on mortality, morbidity, nutrition status, vaccination coverage and reproductive health. However, as in long-standing refugee settings worldwide, beneficiary input and refugee perceptions of healthcare are less easily, and less frequently, assessed.

Quite often in humanitarian efforts, program management is chiefly directed by an organization's mission or tasked according to the interests of funding agencies (Rutta et al. 2005). Meanwhile, the opinions of stakeholders and the desires of program beneficiaries can be neglected, despite their

central role as healthcare recipients. The Sphere Project standards, followed by the humanitarian community as best-practice guidelines, list "Evaluation" as the sixth common standard, whose key indicator requires that "evaluations take account of the views and opinions of the affected population, as well as the host community if different" (The Sphere Project 2004: 39).

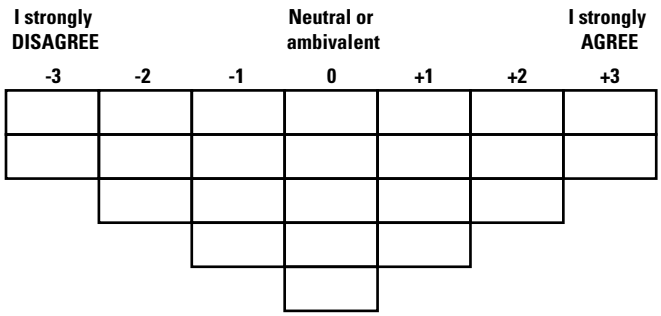
The relative absence of beneficiary input within refugee camps is often a reported result of scarce resources and the lack of technical capacity and manpower available for qualitative data collection and analysis (Greenough et al. 2007). Knowledge, attitude and practices (KAP) surveys and rapid assessment procedures (RAP) are methods commonly used to evaluate beneficiary programming in refugee camps (Manderson and Aaby 1992). These methods are appropriate for collecting data on easily measurable and quantifiable indicators such as mortality and malnutrition rates. They also provide a cost-effective method for continuous, periodic data collection that does not require high levels of expertise or extensive human resources. However, KAP and RAP surveys are ultimately methods of rapid assessment and, therefore, necessarily sacrifice some validity and precision on specific beneficiary perspectives for ease and speed of administration.

In this article we propose an alternative tool for beneficiary participatory program assessment within the refugee setting. By-person factor analysis is a hybrid of qualitative and quantitative methods applied in the scientific study of subjectivity. While long used in a number of other scientific disciplines, this methodology has to our knowledge never previously been used in the refugee setting. Using case studies of its first application within refugee camps, the authors present their experience applying by-person factor analysis in the collection and assessment of beneficiary perceptions of refugee health services in Kenya and Tanzania.

Methods

By-person factor analysis provides a scientific approach to the study of subjectivity while attempting to eliminate the influence of investigator preconceptions. First introduced by British physicist and psychologist William Stephenson in a letter to Nature in 1935, by-person factor analysis has been applied to numerous fields of research, including the fields of political science, social science, psychology and healthcare (Brown 1996). The strength of the methodology lies in its ability to (1) subdivide a study population based upon participants' subjective responses to an issue, (2) evaluate the degree of consensus among participants, and (3) identify any discordant or minority opinions within a study population.

Figure 1. Quasi-normal (Gaussian) grid provided to participants for the force-ranking of statements in by-person factor analysis



The process of by-person factor analysis utilizes a unique combination of qualitative and quantitative methods. First, investigators establish a concourse or collection of perceptions and opinions about the topic under study (Nelson et al. 2005). From this concourse of ideas, 23 written state-

ments are developed that represent the spectrum of opinion within the study population. Members of the community are subsequently invited to individually sort each statement into a specially designed, quasi-normal grid of 23 boxes (Figure 1). In so doing, participants must rank-order the statements as to whether they completely disagree with, feel indifferent or ambivalent toward, or completely agree with each statement.

For the purpose of our health program assessments in the five selected refugee camps of northwestern Kenya and western Tanzania, a large concourse of perceptions and opinions was established through dozens of key-informant interviews, focus group discussions and free-response questionnaires. From the developed concourse, the investigators selected key statements that represented the wide variety of opinion about health-related issues in the refugee camps – issues such as healthcare services, food and nutrition, water and sanitation, community health, mental health, gender-based violence and safety. (The first columns in each of Tables 2 and 3 list the 23 statements used in the Kakuma refugee camp and the Kibondo District refugee camps, respectively.) Utilizing established community health networks, participants at each of the five sites were obtained through open and targeted invitation of program beneficiaries and healthcare staff.

Each participant was given a copy of the quasi-normal grid of 23 boxes and a set of 23 small squares of paper; upon each piece of paper was imprinted one of the 23 statements. Participants were then provided written and verbal instructions on sorting the statements into the grid. Statements with which a participant most strongly disagreed were placed toward the left side of the grid (-3 agreement score), while statements with which a participant most strongly agreed were placed toward the right side of the grid (+3 agreement score). Between these extremes were placed statements about which the participant felt more neutral or ambivalent (0 agreement score). Participants could not augment the grid distribution or place more than one statement into each box in the grid. In this way, participants were compelled to prioritize and rank their perceptions and opinions. Responses remained anonymous throughout in order to facilitate a safe environment for minority or negative viewpoints.

The respondents' completed grid sorts were documented and then entered into and analyzed using PQMethod 2.11, a publicly available by-person factor analysis software package (Schmolck 2002). Given the populations' differing settings and conditions, analysis was completed independently for participants in Kakuma from the participants in the four refugee camps in western Tanzania. Subsequent subgroup analysis further explored differences within the populations.

Data analysis included assessing levels of group agreement and identifying unique respondent types within the study populations. Each respondent type represents a group of individuals who have common perspectives that are unique relative to participants outside of the group. By identifying these unique respondent types within a population, majority and minority opinions can be elucidated. This information allows targeted interventions to directly address each subgroup's distinct concerns. To define and characterize the respondent types, participants who had significant and specific concordance with a single respondent type (i.e., >60% concordance with the respondent type of interest and <30% concordance with remaining types) were closely reviewed to assist in characterizing each respondent type.

These methods – including both regional and site-specific key-informant interviews, focus group discussions, questionnaires and by-person factor analysis exercises – were accomplished by two investigators in Kenya (one week) and two investigators at the four sites in Tanzania (three weeks).

Results

Preparation for by-person factor analysis included approximately 10 to 12 key informant interviews in each country and two focus group discussions at each of the five refugee camps. For by-person factor analysis, a total of 84 individuals – representing various cultural groups and social positions within the refugee camps – were invited to participate: 22 individuals in the Kakuma Refugee Camp in Kenya and a total of 62 individuals within the four Kibondo District refugee camps in western Tanzania (Table 1). Each of the five camps had roughly comparable levels of participation. The

response rate of participants successfully completing the exercise was 96.4%. Participant age ranged from 19 to 60 years, with a mean age of 34.5 years. Forty-two percent of participants were female. Refugees represented 50.6% of participants, refugee community leaders were an additional 17.3% of participants and healthcare workers constituted the remaining 32.1% of participants.

Table 1. Participant demographics for by-person factor analysis

Response rate	96.4% (81/84)
Participation by camps	27.2% from Kakuma Camp, Kenya
	19.8% from Kanembwa Camp, Tanzania
	19.8% from Nduta Camp, Tanzania
	17.3% from Mtendeli Camp, Tanzania
	16.0% from Mkugwa Camp, Tanzania
Age	Range 19-60 years
	Mean 34.5 years
Gender	42.0% female
	58.0% male
Position in the community	50.6% refugee
	17.3% refugee community leader
	32.1% healthcare worker
Ethnic group	60.5% Burundi
	13.6% Congo
	12.3% Sudan
	6.2% Ethiopia
	4.9% Somalia
	1.2% Rwanda
	1.2% Tanzania

Assessing Levels of Agreement

By-person factor analysis allowed for the assessment of consensus within the study populations. Using the data from the Kakuma refugee camp as an example of this assessment capacity, by-person factor analysis revealed significant consensus on several health-related issues. Kakuma participants, on average, felt discrimination from community health workers and did not fully trust them. Healthcare access appeared to be another concern of these participants. Most believed vulnerable groups did not have access to healthcare, there was a long wait for specialty care, the hospital was overcrowded and it was difficult to quickly obtain emergency healthcare at night. There was also significant agreement that assault and lack of food were continuing obstacles to quality refugee health. However, most participants felt that tuberculosis care and mental health programs provided in the camp were adequate.

Comparing Participant Responses by Demographic Types

By-person factor analysis can also be utilized to examine responses across demographic types. Data from the Kibondo District refugee camps illustrate this. In the Kibondo District camps, investigators compared the responses of community members (i.e., refugees), to the responses of health workers, to the pooled responses of all participants (Table 2).

Table 2. Comparison of participant responses by demographic types, -Kibondo District refugee camps, Tanzania

Statements (listed from greatest participant consensus to least consensus)	Averaged level of agreement for each statement		
	All Kibondo participants	Kibondo community members	Kibondo health workers
Patients are prescribed the medicines they need	-0.9	-0.8	-1.1
It is easy for patients to get treatment for sexually transmitted infections	0.5	0.3	0.8
The lines are too long at the outpatient department	0.5	0.6	0.4
The vulnerable groups in the camp do not have good access to healthcare	-0.3	0.1	-0.8
There is good care for women who have problems in childbirth	0.4	0.5	0.3
The health staff are well trained	-0.1	-0.1	-0.2
Chronic diseases are poorly cared for in the camp	-0.1	0	-0.3
Patients receive good quality healthcare in the camps	-0.3	-0.4	-0.2
Refugees trust the community health worker if they have health concerns	0.6	0.1	1.3
Criminals can get away with rapes and other assaults in the camp	-0.2	-0.3	-0.2
Help is available for people who have HIV infection	-0.1	-0.2	0
Domestic violence cases are not taken seriously by the community	-0.3	0.2	-0.9
Waiting for a referral to a specialist doctor takes too long	0.5	0.6	0.5
More families should use family planning services	0	0.2	-0.2
Refugees seek dental care when they have problems with their teeth	-0.1	-0.2	0.1
The pharmacy often lacks the medicines the doctors prescribe	0.6	0.5	0.8
Refugee health workers are treated fairly in terms of salaries and authority	-1.3	-0.7	-2
The inpatient wards are overcrowded	0.9	0.7	1.2
Community health workers place enough importance on disease prevention	0.4	0.3	0.7
Refugees in the supplementary feeding program still go hungry	0.2	0.5	-0.1
Patients cannot get eye care when they need it	-0.3	-0.3	-0.2
Mental health programs are adequate for all of the people who need help	-0.3	-0.7	0.3
Community health workers are poorly trained to answer the health questions of refugees	-0.5	-0.9	0

Note. With each statement, an averaged level of agreement is calculated for all Kibondo participants and for the subgroups of community members and health workers. Agreement levels for each statement correspond to "I strongly disagree" (-3), "I feel ambivalent/neutral" (0), or "I strongly agree" (+3).

Significant consensus on several health-related issues was found. On average, participants felt that patients were not prescribed the medications they needed and that, when medications were prescribed by a doctor, the pharmacy often lacked the medications. (Interestingly, health workers felt this way even more strongly than community members.) There was large consensus that the inpatient wards were overcrowded. Similarly, all tended to agree that patients waited too long for outpatient services (an important exception being services for sexually transmitted infections) and for referral to specialist doctors. Eye care was felt particularly difficult to obtain. On the other hand, participants consistently agreed that there was good care available for women who had obstetric complications. Both community members and health workers felt that refugee health workers were not treated fairly in terms of salaries and authority. There was consensus that community health workers placed adequate importance on disease prevention.

Identifying Distinct Respondent Types

In addition to determining levels of agreement among study participants, by-person factor analysis facilitates the identification of distinct respondent types, or clusters of participants grouped by their common opinions and perceptions. From our Kakuma study, four respondent types were discovered in the population (Table 3). Kakuma Respondent Type 1 individuals (32% of Kakuma participants) were concerned that insecurity and discrimination limited healthcare. They believed that assault and rape were constant problems that were not taken seriously and were not punished. Furthermore, Kakuma Respondent Type 1 individuals stated there was discrimination by community health workers and poor healthcare access for vulnerable groups. Kakuma Respondent Type 2 individuals (involving 14% of Kakuma participants) believed healthcare was getting worse in the refugee camp. They cited poor medication supply, limited food and water, and poor employee training and remuneration. Kakuma Respondent Type 3 individuals (14% of Kakuma participants) were hopeful that conditions were going to improve. Even as they agreed with others that insecurity was a constant threat, especially at night, they believed that rape was taken seriously. This respondent type also stated that mental health and vulnerable group services were good, but drug supply and training programs needed improvement. The last identified group of Kakuma participants, Kakuma Respondent Type 4 (14% of Kakuma participants), advocated improved healthcare access for vulnerable populations and improved tolerance by community health workers. While they did not feel that the clinic lines were too long, they stated that the hospital was overcrowded and that there were long delays to see specialists.

Respondent Type 1 individuals (18.6% of Kibondo participants) were more likely to be refugees and … believed that referral to specialty doctors took too long, chronic diseases were poorly cared for, inpatient wards were overcrowded, individuals in the supplementary feeding program still went hungry.

Similar by-person factor analysis yielded three unique respondent types within the Kibondo District camps of western Tanzania. Kibondo Respondent Type 1 individuals (18.6% of Kibondo participants) were more likely to be refugees and had several recommendations for health program improvement. They believed that referral to specialty doctors took too long, chronic diseases were poorly cared for, inpatient wards were overcrowded, individuals in the supplementary feeding program still went hungry, medications were not adequately prescribed or stocked, mental health programs were not adequate for all who needed them and refugee health staff were treated unfairly in terms of salaries and authority. However, this group did feel that good care was available for women who had difficulties during childbirth. Kibondo Respondent Type 2 individuals (10.2% of Kibondo participants) were predominantly community leaders (67%) and appeared more satisfied with health services. Like Kibondo Respondent Type 1, they believed good care was available for women with

Table 3. Comparison of participant responses by identified respondent types, Kakuma refugee camp.

Statements (listed from greatest participant consensus to least consensus)	Averaged level of agreement for each statement				
	All Kakuma participants	Kakuma Type 1 (32% of participants)	Kakuma Type 2 (14% of participants)	Kakuma Type 3 (14% of participants)	Kakuma Type 4 (9% of participants)
I trust the community health worker if I have health concerns	-1.0	-2	0	0	0
The treatment for tuberculosis in the camp is not adequate	-0.8	0	0	-1	0
The hospital is overcrowded	1.0	2	-1	0	2
Health would improve if refugees had more food	1.1	-1	2	1	1
There is not enough water	0.4	-1	2	1	0
I do not feel discrimination from the camp healthcare providers	-1.5	-3	-1	0	-2
Healthcare in the camp would improve if IRC had better qualified doctors	0.2	0	-1	-1	-1
Mental health programs are not adequate for all of the people who need help	-0.4	0	0	-3	2
The quality of healthcare in the camp is getting worse	0.5	1	3	-1	-1
If I have a health emergency at night I can see the doctor quickly	-2.2	-3	-3	-1	-1
The lack of an x-ray machine delays healthcare	0.9	1	1	1	1
Criminals can get away with rapes and other assaults in the camp	0.5	2	-1	0	0
We have no hope for a better future	0.2	1	0	-2	1
Incentive employees are not treated fairly in terms of salaries and authority	0.4	0	2	2	1
Assault is a constant threat	1.0	3	1	2	-1
Waiting for a referral to a specialist doctor takes too long	1.1	2	1	1	3
The refugee employee training programs in the camp are good	-0.8	-2	-2	-2	3
I do not get the drugs I want at the clinic	0.2	-1	3	2	0
The lines are too long at the IRC clinics	0.4	0	0	0	-3
The vulnerable groups in the camp have access to healthcare	-1.2	-2	-2	3	-2
Chronic diseases are not adequately taken care of in the camp	0.4	1	1	-2	-3
Rape cases are not taken seriously by the camp agencies	-0.1	3	-2	-3	-2
I worry about my safety if I have a health emergency at night	-0.1	-1	-3	3	2

Note. With each statement, an averaged level of agreement is calculated for all Kakuma participants and identified respondent type are compared. Agreement levels for each statement correspond to "I strongly disagree" (-3), "I feel ambivalent/neutral" (0), or "I strongly agree" (+3).
IRC = International Rescue Committee.

obstetric complications. They also stated that vulnerable groups had good access to healthcare, criminals could not get away with rape and other assaults, community health workers were well trained and eye care was available when needed. According to Kibondo Type 2 Respondents, three areas of service limitations were that the pharmacy often lacked medicines doctors prescribed, refugees in the supplementary feeding program still went hungry and mental health programs were inadequate for all who needed them. The last group, Kibondo Respondent Type 3 individuals (10.2% of Kibondo participants), had disproportionately high percentages of women (83%) and health workers (83%). These individuals were largely satisfied with the refugee health program. They felt that the community health workers were well trained and trusted by the refugee community. They believed that help was available for people living with HIV/AIDS, treatment for sexually transmitted infections was readily available and domestic violence was taken seriously by the community. This group uniquely felt that mental health programs were adequate for all those who needed them. The two identified concerns of Kibondo Respondent Type 3 were that inpatient wards were overcrowded and that the refugee health staff were treated unfairly in terms of salaries and authority.

According to Kibondo Type 2 Respondents, … the pharmacy often lacked medicines doctors prescribed, refugees in the supplementary feeding program still went hungry and mental health programs were inadequate for all who needed them

Discussion

Assessing and responding to beneficiary needs is a vital, ongoing responsibility of the international community. However, identifying effective and rapid assessment methods for this purpose has at times been a challenge. The participatory approach of by-person factor analysis may help fill this need. Using examples of its application in refugee camps in Tanzania and Kenya, we illustrate the depth and breadth of information on beneficiary perceptions that can be obtained through by-person factor analysis.

Firstly, not unlike other rapid assessment methods, by-person factor analysis assists in identifying specific needs within a population. For example, among those in the five surveyed camps in Kenya and Tanzania, access to healthcare was a primary concern. Refugee beneficiaries felt that health centres were overcrowded and outpatient care was difficult to access. Policies to improve referrals, decrease waiting times and increase interaction with community health workers may improve refugee perceptions related to these services.

An additional strength of this methodology, however, is its ability to also identify critical issues, such as potential obstacles to improvements, significant divergence of opinions and previously unrecognized subgroup needs. Recognizing and addressing obstacles, discordant opinions and minority needs is important for program viability and for successfully providing services for the entire population. One example of an important identified divergence in opinion in the Kibondo camps related to healthcare access. Most healthcare workers believed that vulnerable groups had good access to healthcare, while community members typically disagreed. Similarly, Respondent Type 1 within Kakuma represented a subgroup of refugees who felt discrimination from community health workers and felt that their concerns were not taken seriously by camp authorities. Now discovered, these important opinion differences and subgroup concerns can be more effectively addressed.

This application of Q-methodology is but one illustration of the functional support academia can provide to the humanitarian community at the local field level. This relationship between NGO program personnel, beneficiaries and academia can be built collaboratively through their respective roles in data collection, systematic participation, and analysis and interpretation. NGOs need evaluative mechanisms that engage beneficiary participation; academia has validated methods but requires meaningful access to populations of interest. Through this exercise, NGOs build institutional and local capacity.

The participatory approach of by-person factor analysis, illustrated here by its application among refugees in Kenya and Tanzania, offers the humanitarian community an additional and effective means of assessing important beneficiary perceptions. The objective of such beneficiary participation is the improvement of healthcare services and health outcomes among refugee recipients. Soliciting beneficiary input is crucial for improving available services to meet the specific needs of the refugee community. Incorporating beneficiary input can also increase refugee satisfaction with services and potentially improve program utilization and health outcomes. Furthermore, facilitating participatory involvement in program design, implementation and evaluation can give refugees a realization of empowerment – essential in an environment in which they often feel powerless to enact change.

Conclusion

The results of these case studies support the benefits and feasibility of implementing by-person factor analysis within a refugee camp setting. Compared with conventional survey methods or other methods of rapid assessment, by-person factor analysis can uncover opinions and perceptions that may not otherwise be apparent to researchers or service providers. In addition, by-person factor analysis can be successfully administered in resource-limited settings among participants with restricted formal schooling.

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Use of Health Services by Women with Gynecological Symptoms in Rural China

Zhen Jiang, School of Health Service Management, Anhui Medical University, Hefei, Anhui Province, China

Debin Wang, School of Health Service Management, Anhui Medical University, Hefei, Anhui Province, China

Qian Hong, School of Health Service Management, Anhui Medical University, Hefei, Anhui Province, China

Nicola Cherry, Department of Public Health Sciences, Albert University

Jing Cheng, School of Health Service Management, Anhui Medical University, Hefei, Anhui Province, China

Jing Chai, School of Health Service Management, Anhui Medical University, Hefei, Anhui Province, China

Sen Yang Department of Dermatology and Venereology, The First Affiliated Hospital of Anhui Medical University, Hefei, Anhui Province, China

Xuejun Zhang, Department of Dermatology and Venereology, The First Affiliated Hospital of Anhui Medical University, Anhui Medical University, Hefei, Anhui Province, China.

Correspondence may be directed to: Xuejun Zhang, Department of Dermatology, The First Affiliated Hospital of Anhui Medical University, Hefei, Anhui Province, China.
Tel. +86(551)5161002, Fax: +86(551)5161016; E-mail: ayzxj@vip.sina.com

Abstract

Background: To examine the relation between demographic factors and symptom type in the use of gynecological health services in rural China.

Methods: Married women aged 19 to 45 years from three rural communities in Anhui province, central China, were invited to participate in a structured interview in the summer of 2006. They provided information on gynecological symptoms, healthcare-seeking behaviour and socio-demographic characteristics. Risk factors were analyzed using logistic regression.

Results: 860/1221(70.4%) reported at least one gynecological symptom during the previous year, with 485 (39.7%) reporting three or more. Of the women with symptoms, 36.7% sought treatment during the previous year. Younger women and those with multiple symptoms were more likely than others to seek treatment. Women with abnormal vaginal bleeding or discharge were more likely to delay seeking treatment. Years of education were strongly related to seeking treatment. More highly educated women and women with a higher household income were more likely than others to seek treatment at the highest level (county or city hospital) of the tertiary healthcare system rather than at a village clinic or township hospital. Women who did not seek treatment were more likely to report that they saw no need than to say that they could not afford care.

Conclusion: There may be a misperception of the need for, and utility of, treatment for gynecological symptoms, particularly in more disadvantaged women. Interventions should both address women's negative perceptions and reinforce the capacity of the local health facilities to ensure effective care.

Introduction

In developing countries, improvement of reproductive health depends strongly on the strengthening of health systems (Maine 2007). In China, by the mid-1970s a highly structured, three-tier healthcare system was established, and it has been strengthened in recent years. Family planning education and counselling are available to rural women at village clinics. Family planning, antenatal and obstetrical services, and treatment of gynecological symptoms are available in township health centres, county hospitals, and county maternal and child-care centres.

Recent reports show that use of antenatal and obstetrical services has increased in rural China, due in part to economic improvements and the increased capacity of the reproductive health services (Ministry of Health 2008a). Analysis of the China National Health Services Survey showed that rates of antenatal examination have increased steadily, from 60% in 1993, to 87% in 1998, to 96% in 2003. Hospital delivery rates have likewise increased from 22% to 41% to 62% during these years (Centre for Health Statistics and Information 2003).

However, use of health services for gynecological disorders has not increased during the same period. (China Gender and Development Organization 2008; Gao and Cai 2003; Guo et al. 2002; Population Family Planning Committee Development Department 2006). National and regional studies indicate that the incidence of gynecological disorders is high. (China Gender and Development Organization 2008). Some 38% to 85% of rural women have been found to complain of at least one symptom that may indicate reproductive-tract infection; however, use of health services has remained low (Gao and Cai 2003; Guo et al. 2002 Population Family Planning Committee Development Department 2006).

Reproductive health covers a broad range of health concerns (World Health Organization [WHO] 2010). In China, it is suspected that gynecological disorders are increasingly affecting rural women's health (China Primary Health Care Foundation 2006). Along with health promotion to enable women to undergo a safe pregnancy and childbirth (Ministry of Health 2008b; The People Net 2005) the next priority issues may be to combat sexually transmitted infections, reproductive tract infections, cervical cancer and other gynecological morbidity. There is a need for accessible and timely healthcare for these disorders and a better understanding of barriers to the use of such services.

The extent to which cultural and psychosocial factors can influence women in traditional and rural settings to seek reproductive healthcare is gaining recognition (Orach et al. 2007). For antenatal and obstetrical care, physical distance from service provision as well as socio-economic factors have been shown to be important (Ensor and Cooper 2004; Filmer and Pritchett 2001; Mumtaz and Salway 2007; Mwifadhi et al. 2007). Rural women may experience the same barriers to seeking gynecological healthcare under the Chinese three-tier rural health system. However, the distinctive difference observed in China between the levels of utilization for these two services may indicate that factors other than socio-economics and distance play an important role in the way in which women seek healthcare for gynecological symptoms.

Previous studies of these symptoms and the use of health services suggest an unmet need in some

segments of society for early diagnosis and treatment of potentially serious gynecological symptoms such as abnormal bleeding or breast abnormalities (Liu et al. 2007; Schettino et al. 2006). There is also a need for services to deal in a rational way with common gynecological complaints such as abnormal vaginal discharge (Patel et al. 2006). Few studies have systematically explored the association between different types of gynecological symptoms and health service utilization. In particular it remains unclear whether different types of symptoms are more likely to be recognized or ignored by women. As rural women in China commonly have no employer or health insurance system to organize and pay for periodic physical examinations, it is for the woman herself to recognize the need for treatment (Jia et al. 2005). In 2008, a national rural health insurance system was established (Ministry of Health 2008b), followed by a cervical cancer screening program initiated in 2009. (Ministry of Health China 2009). Nevertheless, given the rural healthcare system's limited capacity for diagnosis and treatment, it is important to explore which gynecological symptoms trigger healthcare use and to look for ways to promote practical treatment options. This is a question of considerable public health importance, if intervention priorities for this population are to be clarified and met.

We hypothesize that different symptoms may lead to different healthcare-seeking behaviours and to choosing different healthcare providers. If this is true, it would have significant implications for the way reproductive health programs are delivered. If women were more aware of the differential importance of particular symptoms, and primary care workers were better trained to respond, the cost-effectiveness of the very limited resources available for rural women in developing regions would improve.

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We set out to investigate the role of demographic factors and gynecological symptom characteristics in determining healthcare use through a population-based study in rural China.

Methods

Study Design and Target Population

The study used a cross-sectional survey design. Three counties (Feixi, Zongyang and Lujiang) were randomly selected from central Anhui province after stratification on economic levels such that one county with high, one with medium and one with low incomes relative to the rest of the province were selected. In each sampled county, one town was randomly selected and then a random sample taken of five villages associated with the town. All married female residents aged 19 to 45 years in the selected villages were included in the study sample. Data were collected in August and September 2006.

Survey Methods

Female research assistants who had been trained in interviewing conducted face-to-face structured interviews. They explained the objectives of the study and provided assurance of confidentiality. After giving informed consent, participants provided detailed information on demographic and socioeconomic characteristics, on gynecological symptoms and on use of services within the previous 12 months. Participants with limited literacy skills completed the survey verbally in a private room; the remainder completed written questionnaires.

Ethical Approval

The study received ethical approval from the Anhui Medical University Research Ethics Board. During field work, information sheets about the study in three counties were given out, explaining why it was being carried out, by whom, and what it would involve. Written consent of all participants was sought, with oral consent accepted from those unable to write.

The Questionnaire

Demographic factors and gynecological symptoms were identified from a review of the literature. Questionnaires were piloted with 55 rural women to assess the feasibility and clarity of items. The questionnaire consisted of three sections: gynecological symptoms, socio-demographic information, and healthcare utilization.

Gynecological Symptoms

Eight gynecological disorders were identified from the literature (Anderson et al. 2004; Harlow and Campbell 2004; Ryan et al. 1998), and participants were asked if they had experienced any of these during the past year. The classes of symptom were (1) abnormal vaginal discharge (increasing leucorrhea, leucorrhea with odour, leucorrhea with abnormal colour or shape, (2) abnormal uterine bleeding (long duration of menstrual flow, excessive/heavy or profuse bleeding, frequent periods of short cycles, spotting or inter-menstrual bleeding, amenorrhea/no menses for three or more months, oligomenorrhea/menstrual cycles of 35 to 90 days, infrequent menses), (3) abdominal pain (lower backache, abdominal pain not with menstruation, cramps with menstruation), (4) a palpable lump in the abdomen (one that can be touched or felt), (5) vulval itch, (6) abnormal urination (frequent urination, a pressing need to urinate or pain during urination), (7) pain during sexual intercourse, and (8) breast abnormality (palpable axillary lymph node/callosity, palpable lump in the breast, abnormal nipple discharge, red or wrinkled skin).

Socio-demographic Characteristics

Participants provided demographic information including age, education and annual family income. Annual family income was grouped into four levels: <5000 RMB (approximately 600 US dollars), 5000 to 10,000 RMB, 10,000 to 15,000 RMB and ≥15,000 RMB. Education was also grouped into four levels: illiterate and semi-illiterate, 1 to 5 years' education, 6 to 9 years' education and 10 years' education or more.

Healthcare Utilization

Questions focused on treatment for the most recent symptom, asking:

1. Did you seek treatment for the most recent gynecological symptoms [of the eight listed above] during the previous year? Response options were yes and no. Where a participant reported more than one symptom, the symptom precipitating the healthcare-seeking behaviour could not be isolated;
2. How many days after you first experienced the symptom did you go to see a doctor? Response options were 0 to 1 day, 2 to 3 days, 4 to 6 days, 1 week to 1 month and >1 month; timely treatment was defined as a delay of ≤1 month; and
3. In which of the following health institutions have you sought treatment for the most recent symptom? The treatment options listed were village clinic, township health centre, city/county hospital, and provincial and other hospital. In the event that the woman reported using more than one institution, the highest level was coded: 1 if the highest level was a village clinic, 2 if the highest level was a township hospital, 3 if the highest level was in the city/county, and 4 if the highest level was a provincial/other hospital.

Statistical Methods

The distribution of symptoms, treatment, timely treatment and health institution by demographic factors was summarized in a descriptive analysis. Logistic regression was used to explore the relationships between demographic factors, number of symptoms and healthcare use, first in a univariate analysis and then in multivariate analyses, taking account first of the number of symptoms and second of the nature of the symptoms. All *p*-values were assessed using two-sided tests with $p < .05$ taken as the criterion for statistical significance. Analyses were conducted using SPSS (Version 11.5).

Results

Among 1398 eligible women identified, 1221 agreed to participate, a response rate of 87.3%.

Characteristics of Study Participants

The three communities were equally represented. Table 1 shows that 392, 429 and 400 participants were recruited from low, middle and high economic regions, respectively. Nearly half the women (598) were aged 30 to 39. For the large majority (1141; 93.4%) education level was less than 10 years. Approximately three quarters of women (928) were from families whose income was under 15,000 RMB ($2000 US) per year. Both years of education and family income were related to the economic level of the region. The proportion of women with 10 or more years' education was greater (12.3%) in the highest economic region than in the lowest (3.8%). Similarly, 35.5% of women in the highest economic region had a family income of ≥15,000 RMB, compared with 12.9% in the lowest.

Gynecological Symptoms

Seventy percent (860/1221) of women reported experiencing gynecological symptoms during the previous year. There was no significant difference between those with and without symptoms for any of the socio-demographic characteristics, although women under 30 years appeared somewhat more likely to report one or more symptoms than older women, and women with family incomes <5000 RMB were somewhat less likely to report symptoms than other women (Table 1, first column).

Among the 1221 participants, 15.5% (189/1221) reported experiencing only one gynecological symptom during the previous year, 15.2% (185/1221) had two symptoms, and 39.7% (485/1221) had three or more.

The most commonly reported symptoms were abnormal vaginal discharge (697/1221; 57.1%), vulval itch (380/1221; 31.1%), abnormal urination (266/1221, 21.8%), abdominal pain (255/1221; 20.9%) and pain during intercourse (199/1221; 16.3%) (Table 2, first column). The rate of each symptom showed no significant difference by region, age, education and income (data not shown), except for reported breast abnormalities, where the rate was higher (6.7%) in the 30 to 39 year group than in younger (2.4%) or older (3.0%) women (chi-square = 10.87; $p < .01$).

Healthcare Utilization

Of the 860 women with symptoms in the last year, 316 (36.7%) sought healthcare for the most recent symptom. The proportion doing so, and the proportions seeking treatment in a timely fashion, are shown in Columns 2 and 3 of Table 2 and in Figure 1. Here, significant differences were found with demographic factors. Women from poorer regions, of younger age and higher education level were more likely to seek treatment (Table 3, middle columns). Of those 316 seeking treatment, 47 (14.9%) sought healthcare within one day of the symptom's appearance, 133 (42.1%) within two to seven days, 64 (20.3%) between one and four weeks, and 72 (23%) sought care only after one month or more. No statistical difference was found in timely treatment (defined as less than one month) by demographic factors (Table 3, final columns), although women aged 30 years or more appeared somewhat more likely to delay consulting a doctor, as did women with more than one symptom.

Table 1. Summary data on prevalence of any symptom complaints, any treatment seeking and treatment ≤1 month during the previous year

	Any symptom[a]					Any treatment[b]					Treatment in ≤1 month[c]				
	N	n	%	χ^2	*p*(trend)[d]	N	n	%	χ^2	*p*(trend)[d]	*N*	n	%	χ^2	*p*(trend)[d]
Region economic level															
Low	392	276	70.4	0.13	0.718	276	125	45.3	5.40	0.021	125	102	81.6	3.63	0.057
Middle	429	307	71.6			307	92	30.0			92	20	21.7		
High	400	277	69.3			277	99	35.7			99	29	29.2		
Age															
≤29	252	188	74.6	1.10	0.295	188	86	45.7	15.14	0.000	86	12	13.9	3.55	0.060
30–39	598	412	68.9			412	157	38.1			157	41	26.1		
≥40	371	260	70.1			260	73	28.1			73	19	26.0		
Education															
None	168	111	66.1	0.01	0.927	111	35	31.5	6.12	0.013	35	9	25.7	0.32	0.571
1–5	488	355	72.7			355	123	34.6			123	29	23.6		
6–9	485	341	70.3			341	130	38.1			130	28	21.5		
10+	79	53	67.1			53	28	52.8			28	6	21.4		
Income[e]															
<5000	119	77	64.7	0.65	0.421	77	31	40.3	4.61	0.032	31	8	25.8	0.36	0.545
5,000–10,000	385	279	72.5			279	91	32.6			91	19	20.8		
10,000–15,000	424	294	69.3			294	95	32.3			95	27	28.4		
≥15,000	286	207	72.4			207	98	47.3			98	18	18.4		
Number of symptoms															
1						189	56	29.9	8.74	0.003	56	47	83.9	3.23	0.072
2						185	61	33.0			61	50	82.0		
3 and more						485	199	41.0			199	147	73.9		

[a]The total sample in this column is 1221; % means the percentage of responsive women with any symptom.
[b]The total sample in this column is 860; % means the percentage of symptom women seeking treatment.
[c]The total sample in this column is 316; % means the percentage of treatment women seeking treatment ≤1 month.
[d]*p* (trend) for Linear-by-Linear Association based on χ^2 test.
[e]Seven participants did not report their income.

Table 2. Gynecological symptoms reported and treated

Symptom	Number of women with complaint in the last 12 months (%)[a]	Proportion of women who sought treatment for a single symptom (%)[b]	Proportion of women who sought treatment in for a single symptom in ≤1 month (%)[b]
Abnormal vaginal discharge	697 (57.1%)	24/92 (26.1)	17/24 (70.8)
Abnormal uterine bleeding	66 (5.4%)	3/3 (100)	2/3 (66.7)
Abdomen lump	33 (2.7%)	0/0	–
Abdomen pain	255 (20.9%)	4/21 (19.0)	4/4 (100)
Vulval itch	380 (31.1%)	16/34 (47.1)	15/16 (93.8)
Abnormal urination	266 (21.8%)	7/18 (38.9)	7/7 (100)
Pain during sexual intercourse	199 (16.3%)	1/17 (5.9)	1/1 (100)
Breast abnormality	57 (4.7%)	1/4 (25.0)	1/1 (100)

[a]The total sample in this column is 1221.
[b]Women (*n* = 189) complaining of one symptom only (see text) of whom 56 sought treatment, 47 in ≤1 month.

Figure 1. Treatment and timely treatment by regional economic level, education, age and income

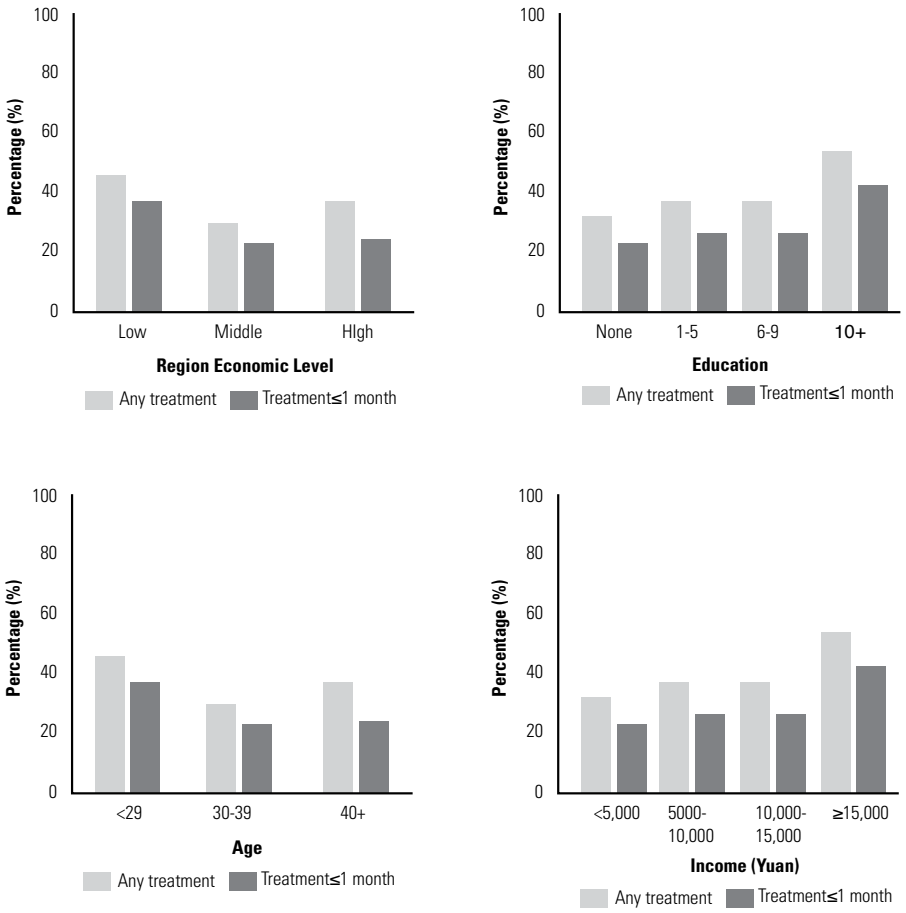

Table 3. Demographic, symptom number and treatment information on the study sample (univariate analysis)

Characteristics	Any symptom		Any treatment		Treatment in ≤1 month	
	OR	95% CI	OR	95% CI	OR	95% CI
Region economic level						
Low	1	1	1	1	1	1
Middle	1.0	0.8–1.4	0.51	0.3–0.7	0.81	0.4–1.6
High	0.9	0.7–1.3	0.67	0.4–0.9	0.54	0.3–1.0
Age						
<29	1	1	1	1	1	1
30–39	0.7	0.5–1.0	0.72	0.5–1.0	0.46	0.2–0.9
40+	0.8	0.5–1.1	0.46	0.3–0.7	0.46	0.2–1.0
Education						
None	1	1	1	1	1	1
1–5	1.4	0.9–2.0	1.15	0.7–1.8	1.12	0.4–2.7
6–9	1.2	0.8–1.8	1.34	0.8–2.1	1.26	0.5–3.0
10+	1.0	0.6–1.8	2.43	1.2–4.8	1.27	0.4–4.1
Income						
<5000	1	1	1	1	1	1
5000–10000	1.4	0.9–2.2	0.72	0.4–1.2	1.32	0.5–3.4
10000–15000	1.2	0.8–1.9	0.71	0.4–1.2	0.87	0.3–2.2
≥15000	1.4	0.9–2.2	1.33	0.8–2.3	1.55	0.6–4.0
Number of symptoms		—				
1			1	1	1	1
2			1.17	0.7–1.8	0.87	0.3–2.3
3 and more			1.65	1.1–2.4	0.54	0.3–1.2

Among those reporting only one symptom, treatment was sought most frequently by the small number of women with abnormal uterine bleeding and least by those with pain during intercourse; timely treatment seeking was lowest for those with abnormal bleeding or discharge (Table 2, Columns 2 and 3).

Of the 316 women seeking treatment, 308 reported the health institution they used. Nearly 10% of women (40) sought treatment from more than one health institution. Referring to the highest institutional level reported, 14.6% of women used only the village clinic, 46.4% women the township health centre, 26.9% the city/county level and 12.0% sought treatment in provincial/other hospitals (Table 4).

Table 4. Demographic factors and selection of health institution for women seeking treatment (*n* = 308)[a]

Variable	*n*	Village clinics			Township health center			City/county hospital			Provincial/other hospital		
		n	%	*p*(trend)[b]	*n*	%	*p*(trend)[b]	*n*	%	*p*(trend)[b]	*n*	%	*p*(trend)[b]
Region economic level													
Low	124	21	16.9	0.236	68	54.8	0.000	18	14.5	0.000	17	13.7	0.022
Middle	88	11	12.5		45	51.1		15	17.0		17	19.3	
High	96	13	13.5		30	31.3		50	52.1		3	3.1	
Age													
<29	83	11	13.3	0.762	37	44.6	0.443	27	32.5	0.599	8	9.6	0.534
30–39	153	23	15.0		75	49.0		35	22.9		20	13.1	
40+	72	11	15.3		31	43.1		21	29.2		9	12.5	
Education													
None	34	5	14.7	0.106	19	55.9	0.085	2	5.9	0.000	8	23.5	0.218
1–5	119	24	20.2		53	44.5		30	25.2		12	10.1	
6–9	127	13	10.2		65	51.2		35	27.6		14	11.0	
10+	28	3	10.7		6	21.4		16	57.1		3	10.7	
Income													
<5000	31	5	16.1	0.026	16	51.6	0.907	4	12.9	0.028	6	19.4	0.529
5000–10000	89	17	19.1		43	48.3		20	22.5		9	10.1	
10000–15000	91	17	18.7		39	42.9		24	26.4		11	12.1	
≥15000	96	6	6.3		45	46.9		34	35.4		11	11.5	
Number of symptoms													
1	53	13	24.5	0.013	23	43.4	0.198	10	18.9	0.022	7	13.2	0.464
2	60	11	18.3		30	50.0		16	26.7		3	5.0	
3 and more	195	21	10.8		90	46.2		57	29.2		27	13.8	
Total	308	45	14.6		143	46.4		83	26.9		37	12.0	

[a]Eight women did not report the health institution selected.
[b]*p*(trend) for Linear-by-Linear Association based on χ^2 test.

Among women with symptoms who had not consulted a doctor (544/860), the reasons given for not seeking healthcare were: believing this to be unnecessary (385/544; 70.8%), high medical expense (56/544; 10.3%), having no time (51/544; 9.4%), feeling too shy to see a doctor (50/544; 9.2%), difficulty traveling to the clinic (9/544; 3.5%) and other reasons (52/544; 9.6%).

We examined the choice of health institution by region, age, education, income and number of symptoms (Table 4). In the most wealthy economic region, more than half the women chose treat-

Table 5. Factors associated with reproductive health service use (multivariate analysis)

Explanatory variable	Dependent variable: any treatment for symptom (n = 860)		Dependent variable: treatment in ≤1 month (n = 316)	
	Model 1 (exp(B), 95% CI)	Model 2 (exp(B), 95% CI)	Model 3 (exp(B), 95% CI)	Model 4 (exp(B), 95% CI)
Region economic				
Low	1	1	1	1
Middle	0.52 (0.4–0.7)*	0.54 (0.4–0.8)*	0.76 (0.4–1.5)	0.74 (0.3–1.5)
High	0.59 (0.4–0.9)*	0.58 (0.4–0.8)*	0.47 (0.2–0.9)**	0.50 (0.2–1.0)
Age				
<29	1	1	1	1
30–39	0.96 (0.6–1.4)	0.97 (0.6–1.5)	0.44 (0.2–1.0)**	0.40 (0.2–0.9)**
40+	0.58 (0.3–0.9)**	0.56 (0.4–0.9)*	0.45 (0.2–1.1)	0.38 (0.2–0.9)**
Education				
None	1	1	1	1
1–5	1.44 (0.8–2.3)	1.40 (0.8–2.3)	1.37 (0.5–3.6)	1.60 (0.6–4.5)
6–9	1.63 (0.9–2.7)	1.59 (0.9–2.7)	1.12 (0.4–3.0)	1.18 (0.40–3.2)
10+	2.79 (1.2–6.1)**	2.71 (1.2–6.0)	0.94 (0.2–3.8)	0.88 (0.20–3.7)
Income (RMB)				
<5000	1	1	1	1
5000–10000	0.70 (0.4–1.2)	0.69 (0.4–1.2)	1.35 (0.5–3.6)	1.30 (0.5–3.7)
10000–15000	0.67 (0.4–1.2)	0.68 (0.4–1.2)	0.90 (0.3–2.4)	0.93 (0.3–2.6)
≥15000	1.1 (0.6–1.9)	1.1 (0.6–2.0)	1.65 (0.6–4.8)	1.59 (0.5–4.7)
Number of symptoms				
1	1	–	1	–
2	1.20 (0.8–1.9)	–	0.83 (0.3–2.2)	–
3 and more	1.67 (1.1–2.4)*	–	0.53 (0.2–1.2)	–
Symptom 1 (yes/no)	–	1.22 (0.8–1.8)	–	0.40 (0.2–0.9)**
Symptom 2 (yes/no)	–	1.59 (0.9–2.7)	–	0.40 (0.2–1.0)**
Symptom 3 (yes/no)	–	1.37 (0.6–3.0)	–	1.46 (0.4–5.9)
Symptom 4 (yes/no)	–	1.12 (0.8–1.6)	–	0.71 (0.40–1.3)
Symptom 5 (yes/no)	–	1.76 (1.3–2.4)*	–	1.00 (0.6–1.8)
Symptom 6 (yes/no)	–	1.07 (0.8–1.5)	–	0.92 (0.5–1.7)
Symptom 7 (yes/no)	–	0.74 (0.5–1.1)	–	0.64 (0.3–1.3)
Symptom 8 (yes/no)	–	0.99 (0.5–1.8)	–	0.96 (0.3–2.9)

Note. exp(B) and 95% CI of independent variables in each model were listed, and – means that the variable was not included in the model.
In Models 2 and 4, exp(B) for each symptom means the difference in (timely) treatment seeking between women with and without that symptom.
Symptoms: 1 = abnormal vaginal discharge, 2 = abnormal uterine bleeding, 3 = abdomen lump, 4 = abdomen pain, 5 = vulval itch, 6 = abnormal urination, 7 = pain during sexual intercourse, 8 = breast abnormality.
*$p < .01$; **$p < .05$.

ment at the city/county hospital compared with only about one in six of women in the poorer region (p = .000). Women were more likely to make this choice as educational level increased (p = .000). Those with high incomes and those with many symptoms were more likely to use the city/county hospitals and less likely to use village clinics.

Table 5 present the results of models constructed to take account of demographic and socio-economic factors on seeking treatment and on the timeliness of presentation to the doctor. Models 1 and 2 were developed to examine factors associated with treatment seeking, having taken account of numbers of symptoms (Model 1) and type of symptoms (Model 2). In Model 1, having adjusted for all other factors, we found that women of age 40 years or older were less likely to seek treatment, as were those from the wealthier region. Women with higher educational levels and those with three or more symptoms were more likely to seek treatment. There was little difference in treatment seeking by type of symptom (Model 2), but vulval itch, and perhaps abnormal uterine bleeding, were positively associated with the likelihood of treatment. Models 3 and 4 were constructed to examine factors associated with timely treatment seeking. Women in the most affluent region were less likely to seek timely treatment, as were women aged 30 to 39 years compared with those aged <30 years (Model 3). Those with more symptoms were somewhat less likely to seek treatment within one month than women with fewer symptoms. Women with symptoms of abnormal vaginal discharge and abnormal uterine bleeding were less likely to seek timely treatment than those with other symptoms (Model 4).

Discussion

Safe and appropriate management of gynecological symptoms requires prompt action from women as well as access to appropriate health clinics. Understanding the factors associated with seeking healthcare that either facilitate or act as a barrier can help in designing population-sensitive programs to encourage rational use of services.

This study identified demographic and symptom characteristics associated with use of healthcare for gynecological symptoms among women in rural China. These findings suggest ways to improve timely, safe and rational use of services.

Understanding the factors associated with seeking healthcare that either facilitate or act as a barrier can help in designing population-sensitive programs to encourage rational use of services.

Effects of Demographical and Community Factors on Treatment Seeking

Age, education, income and region were shown to be associated with aspects of treatment seeking and choice of institution. Young women sought more treatment than older ones, but age did not affect choice of health institution. Women in the region with the highest economic level sought less treatment, and less timely treatment, compared with those in the middle and lowest economic regions. (see Figure 1). Women from families with the highest income sought treatment more from county/city hospitals and less from village clinics than those with the lowest family income. The women with 10+ years of education were more likely than the less educated both to seek treatment and to attend the county/city hospital (Table 4).

Besides the effects of demographic factors, there are may be other cultural–social–community factors that contribute to treatment-seeking behaviour. Both social network (Miltiades and Wu 2008) and place of residence (Ham and Lee 2007) have been shown to be associated with health service utilization. Women's traditional inferior status in rural China may partly explain the gap between the use of antenatal and obstetrical services and the use of other gynecological services. In our study area, it was commonly believed that antenatal and obstetric care was a family matter,

linked to the family's future development, while gynecological disorders were a problem only for the woman herself. Further, traditional cultures of silence surrounding gynecological symptoms may inhibit women from obtaining information about it or from seeking services (Harlow and Campbell 2004).

Women's traditional inferior status in rural China may partly explain the gap between the use of antenatal and obstetrical services and the use of other gynecological services.

Effect of Symptoms on Treatment Seeking

It has been argued that health service seeking and delayed treatment are affected by the severity of the symptom (Aroian and Vander Wal 2007), symptom recognition (Rodriguez et al. 2001) and individual interpretation of the symptom, including the awareness of the potential risk (Armfield et al. 2007; Patel et al. 2007). Our results support these earlier findings.

Nearly 45% (385/860) of women who reported one or more symptom did not seek treatment because they felt this was unnecessary. Only 28% women with symptoms (244/860) sought treatment within one month. These results suggest that the symptoms were not recognized as a threat to health. The resulting delay in treatment may result in more serious or chronic gynecological conditions. It strongly indicates an urgent need to promote the awareness of the potential risk and importance of early detection and diagnosis in rural areas. Patient education programs should make efforts to improve understanding and recognition of symptoms.

In this study the most common gynecological symptoms among women of reproductive age were abnormal vaginal discharge (57.1%) and vulval itch (31.1%). This is concordant with reports from other countries, although the symptom complaint rate differs among regions (Patel et al. 2005; Welsh et al. 2004). Vaginal symptoms appear to be one of the most common reasons for gynecological consultation worldwide (Anderson et al. 2004). Our research suggests that women with vulval itch were more likely to seek treatment than women who complained of other symptoms. But women with symptoms of abnormal vaginal discharge or abnormal uterine bleeding were both less likely to seek healthcare within a month of symptoms developing. Both these symptoms may indicate, at least in some women, serious conditions requiring prompt interventions. They are easily recognized by the woman, raising questions about why treatment is delayed.

Previous evidence has suggested that psychosocial factors correlate with treatment seeking, including initial emotional distress, fear of the consequences (Matasha et al. 1998), fear of disclosure of symptoms, negative attitudes toward physicians (Mbizvo et al. 1997), pessimistic beliefs about the consequences of treatment, lower perceived risk, not wanting to think about symptoms (Aroian and Vander Wal 2007) and optimism (Rodriguez et al. 2001). Whether the same psychological states may play a role in delaying recognition and treatment of both abnormal discharge and bleeding needs to be explored in future research.

Further, our findings suggest that among women who seek treatment, those with three or more symptoms are somewhat less likely to seek timely treatment than women with one or two symptoms. The vicious cycle of symptom fear found in other diseases (Armfield et al. 2007) may also exist in women with gynecological symptoms, whereby women with greater fear are more likely to delay treatment, leading to more extensive symptom problems. So understanding the extent to which these elements, such as symptom perception, psychological factors and timely treatment seeking, are interacting in rural China may be of considerable relevance to the planning of interventions to improve gynecological health.

Building Grass-roots Capability

Analysis within the tertiary (village–township–county) health service system framework in rural

China gives some detailed clues on how to approach grass-roots capability building to promote reproductive health.

In our study area, a woman who elects to use the county/city hospital rather than lower-level facilities seeks care at a greater distance and a higher price. It was found that women in the area with higher economic status seek care less frequently and with less timely use of services. Preference for the most costly, higher-level heath institutions may be one reason for them to put off seeking care. If increasing numbers of women develop the same preference for care at a higher-level institution, this may reduce the viability of the grass-roots health institutions (village clinics, township health centres), potentially weakening access to these facilities by less privileged women. The importance of meeting women's changing demands and winning their confidence in rural health institutions must be recognized during the rural health system rebuilding process.

To promote appropriate use of services, physicians and others in the grass-roots institutions need training to understand the women's perceptions of their gynecological symptoms, to assess mental health and other co-morbidities and to provide routine testing for bacterial diagnosis, so paving the way for etiological treatment algorithms and referral of more serious conditions.

The aim of this study was to quantify the extent to which demographic factors and symptoms are associated with use of gynecological healthcare. A limitation of the study is that use of healthcare services was self-reported; historical chart reviews were not feasible due to the poor quality of records in rural China. However, self-reported service utilization has been shown to be valid and reliable (Montano and Phillips 1995). The way in which symptom information was collected precluded clear attribution of treatment seeking to a particular symptom where more than one symptom was experienced during the 12-month period, and this limits the certainty with which conclusions can be drawn about the impact of each symptom. It is also recognized that a comprehensive reproductive health service would include counselling, advice and preventive healthcare; information on these aspects was not collected as they are very rare in rural China.

The strengths of the study include representative sampling and the successful recruitment of a large sample of women from this under-studied rural Chinese population. Our findings contribute to knowledge of women's use of healthcare services for gynecological complaints in rural China, highlighting the contributions of demographic factors and symptom characteristics and, importantly for future planning, describing for the first time factors associated with choice of healthcare provider.

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HIV/AIDS Awareness and Knowledge among Secondary School Students in China

Qun Zhao, Pediatric Prevention Research Center, Wayne State University School of Medicine, Detroit, Michigan, United States

Xiaoming Li, Pediatric Prevention Research Center, Wayne State University School of Medicine, Detroit, Michigan, United States

Bonita Stanton, Pediatric Prevention Research Center, Wayne State University School of Medicine, Detroit, Michigan, United States

Rong Mao, Nanjing University Institute of Mental Health, Nanjing, Jiangsu Province, China

Jing Wang, Nanjing University Institute of Mental Health, Nanjing, Jiangsu Province, China

Lingran Zhong, Nanjing University Institute of Mental Health, Nanjing, Jiangsu Province, China

Hongshia Zhang, Nanjing University Institute of Mental Health, Nanjing, Jiangsu Province, China

Correspondence may be directed to: Xiaoming Li, PhD, Pediatric Prevention Research Center, Wayne State University School of Medicine, 4707 St. Antoine, Suite W534, Detroit, MI 48201-2196, Tel: 313-745-8663, Email: xiaoming_li@wayne.edu, Fax: 313-745-4993

Abstract

With a goal of helping design appropriate HIV/AIDS education and prevention programs for adolescents in China, we analyzed data from 995 secondary school students in Nanjing. Our analysis examined the students' sources of HIV/AIDS information and assessed the overall level, and possible gender and grade (middle school vs. high school) differences, in their HIV/AIDS awareness and knowledge. Data in the current study indicated an overall low and inconsistent level of AIDS knowledge among secondary school students in China. Most of the students could identify models of HIV transmission, but a large proportion held misconceptions regarding symptoms, activities that did not transmit the virus, treatment and preventive measures. The level of using school, family and peers for obtaining information about HIV/AIDS was generally low. There was a discrepancy between the level of utilization and trust of mass media as the main source of HIV/AIDS knowledge. Findings are discussed in terms of implications for HIV/AIDS prevention and education among adolescents in China.

Introduction

While the actual human immunodeficiency virus (HIV) seroprevalence in China remains uncertain, the current official estimate of numbers of persons infected exceeds 740,000 (China Daily 2009). The majority of reported cases are young adults from 20 to 39 years of age (Chen et al. 2004).The steady increase of HIV infection in China underscores the urgent need for education and intervention efforts (Gill 2006; Wu et al. 2007). One area of concern for the Chinese government has been the low level of HIV/AIDS awareness and knowledge among the general population (Gill 2006; Wu et al. 2007). While still controversial (Helweg-Larsen and Collins 1997; Svenson et al. 1997), research in the United States and other Western countries has suggested that sufficient knowledge regarding AIDS is a necessary, albeit inadequate, first step toward effective AIDS prevention and intervention efforts (DiMatteo 1991; Fisher and Fisher 1992). Global literature has found that lack of knowledge is often accompanied by initiating or maintaining risky behaviour, limited adoption of preventive measures and negative attitudes toward people living with HIV and AIDS (Herek et al. 2002). The Chinese government has repeatedly emphasized the importance of AIDS knowledge and education (e.g., State Council 1998; Wu et al. 2007).

While limited data are available about the level of HIV/AIDS awareness and knowledge among adolescents and young adults, existing studies in China suggest an inadequate level of AIDS knowledge and awareness for young adults and other populations. For example, a previous study among 1081 students from eight colleges in two metropolitan areas (Beijing and Nanjing) revealed an inconsistent level of AIDS knowledge among students, with a significant gender and grade difference (Li et al. 2004). While HIV/AIDS knowledge is limited among young adults and in the general population in China, lack of knowledge among adolescents might be even more alarming. This population is at a critical stage of developing sexual intentions and behaviours and forming attitudes toward sexuality and HIV/AIDS-related issues. Because the behaviours and attitudes of a new generation of young people will affect China's future HIV/AIDS epidemic, education and prevention efforts targeting adolescents have great potential to curtail that epidemic. To develop culturally and developmentally appropriate HIV/AIDS education and prevention programs among adolescents in China, it is necessary to assess their knowledge and awareness of the disease. However, with a few exceptions (e.g., Ip et al. 2001), most existing studies of HIV/AIDS knowledge and attitudes among young people were conducted in college populations (Gao et al. 2001; Higgins and Sun 2007; Li et al. 2004), and limited data are available for secondary school students. Therefore, the current study was designed to assess the overall level of HIV/AIDS awareness and knowledge and to explore possible gender and grade (i.e., middle school vs. high school) differences in AIDS knowledge among secondary school students. The study goal was to help design appropriate HIV/AIDS education and prevention programs for adolescents.

Methods

Participants

Data were collected from 10 secondary schools (N = 995) in Nanjing, the capital city of Jiangsu province, with a population of 5.3 million. Secondary education in China consists of middle schools (Grades 7 through 9) and high schools (Grades 10 through 12). The local research team members, who were educational researchers in Nanjing and had extensive experience in conducting research in the local schools, were asked to identify schools based on a number of criteria. Participating schools had to serve the general public from a wide range of socio-economic backgrounds and had to be representative of local schools in terms of number of student enrolled and student–teacher ratio. The study protocol was approved by the Institutional Review Boards at West Virginia University in the United States and the Institute of Higher Education Research at Nanjing University in China.

Survey Procedure

School administrators were approached for permission to conduct the survey in their schools. Once the local research team received this permission, they randomly approached classrooms in the schools

and recruited students in the classrooms. Approximately 100 students were recruited from each participating school. The research team informed the students that the survey was for research only and that participation was voluntary. Informed consent was obtained before students participated in the survey. A self-administered questionnaire was distributed to the students in attendance in the selected classrooms on the day of survey. Teachers (including those who provided assistance with recruitment) were asked to leave the classrooms during survey administration. Responses were anonymous, and participants were assured of the confidentiality of their response. Each participant was assigned an arbitrary identification number. No identifiable personal information was recorded in the survey or database. Approximately 99% of those approached agreed to complete the questionnaire.

Measures

Individual characteristics. Individual characteristics assessed were gender, age, grade, ethnicity (Han or non-Han, with Han accounting for 92% of the total population nationwide), school performance (4-point scale ranging from "mostly A's" to "mostly D's") and perceived physical health (4-point scale ranging from "excellent" to "poor"). Students were also asked whether they were student leaders or representatives of various groups in the school (e.g., study group, students' clubs and class- or school-wide organizations). They were also asked whether they received an allowance from parents and whether they were an only child. As well, they were asked if they were dating and whether they had engaged in a number of pre-coital activities (e.g., hugging, kissing and foreplay).

Family characteristics. Students were asked about their family composition (e.g., living with both birth parents, parents divorced). Paternal and maternal education levels were measured on a 6-point scale ranging from "below elementary school" to "graduate school." Paternal and maternal occupations were measured using an 11-point response option (e.g., workers, peasants, professionals, administrators, government employees, unemployed). Perceived family economic status was measured using family monthly income on a 6-point scale: below 300 yuan, 300–500, 500–1000, 1000–3000, 3000–5000 and more than 5000 yuan (6.82 Chinese yuan = approximate 1 US dollars).

HIV/AIDS awareness. Students were asked about their perceived overall AIDS awareness on a 4-point scale: "a lot," "some," "little" and "nothing." Students were also asked whether they knew that AIDS is caused by a virus called "human immunodeficiency virus" (yes/no).

Source of AIDS information. Students were asked whether they had received AIDS information in the past month from any of 16 sources (e.g., television, radio, magazine, newspaper and billboard). They were asked to select one source they believed could provide the most reliable information. As well, they were asked whom they would turn to if they had a question about AIDS (e.g., doctors, parents, teachers, friends or an AIDS hotline).

AIDS knowledge. There were three sets of 25 AIDS knowledge questions in different formats. The first consisted of 11 true/false items assessing knowledge of definition and causation. The second contained 12 questions querying modes of HIV transmission on a 5-point scale (very likely, likely, not sure, unlikely and very unlikely). For the purpose of data analysis, the "very likely" and "likely" responses were combined into "likely." Similarly, "unlikely" and "very unlikely" were combined into "unlikely." The third set consisted of two questions about AIDS symptoms and preventive measures, with a 4-point scale ranging from "strongly agree" to "strongly disagree." Responses were combined into two categories, "agree" (strongly agree and agree) and "disagree" (disagree and strongly disagree).

These 25 items were reorganized into five categories of AIDS knowledge: AIDS definition/symptoms (three items), true transmission modes (four items), false transmission modes (ten items), clinical outcomes (three items) and treatment/prevention (five items). The percentage of correct answers was used as a composite score for each of the categories.

Analysis

First, differences in individual and family characteristics by gender and grade (i.e., middle school vs. high school) were examined using ANOVA (for continuous variables) and the Chi-square test (for categorical variables). Second, the associations between AIDS awareness and selected individual

and family characteristics were assessed using ANOVA or the Chi-square test. Third, sources of AIDS knowledge were examined by gender and grade. The "most reliable" ranking was calculated using percentage of endorsement for each of the information resources. Fourth, AIDS knowledge was examined by gender and grade using the Chi-square test. Finally, general linear model (GLM) analysis was performed to assess the effects of gender, grade and their interaction on AIDS knowledge. To control for the potentially confounding effect of family socio-economic status (SES), family income was employed as a proxy of family SES to be included in GLM analysis as a covariate.

Results

Sample Characteristics

The sample consisted of 41% middle school students and 59% high school students, with equal proportions of males and females. The mean age was 15.16 years, with 13.75 for middle school students and 16.10 for high school students. Ninety-six percent of the sample was of Han ethnicity, and 89% lived with both birth parents. As shown in Table 1, there were some gender and grade differences in demographic characteristics. More female than male students reported being a student/club leader (57% vs. 49%; $p < .01$), but fewer of them reported excellent/good health (74% vs. 82%; $p < .01$). More middle school than high school students reported having divorced parents (12% vs. 6%; $p < .0001$) and receiving top academic performance (e.g., mostly A's) in school (24% vs. 11%; $p < .0001$). As well, middle school students reported a higher level of parental education, although only the difference regarding maternal education reached statistical significance ($p < .01$). Consistent with their developmental stages, more high school than middle school students reported dating (27% vs. 8%; $p < .0001$) and engaging in pre-coital activities (23% vs. 13%; $p < .0001$).

Table 1. Sample characteristics of 995 secondary students in China

		Gender		Grade	
	Overall	Male	Female	Middle school	High school
N (%)[a]	995 (100%)	495 (50%)	487 (50%)	408 (41%)	586 (59%)
Mean age (*SD*)	15.16 (1.37)	15.20 (1.34)	15.12 (1.39)	13.75 (.69)	16.10 (.76)****
Boys	50%	–	–	53%	49%
High school	59%	58%	61%	–	–
Han ethnicity	96%	97%	94%	95%	96%
Single child	93%	94%	92%	93%	93%
Student/club leaders	53%	49%	57%**	52%	53%
Excellent/good health	78%	82%	74%**	79%	78%
Had allowance	59%	56%	61%	60%	59%
Mostly A's at school	17%	15%	18%	24%	11%****
Dating	19%	21%	17%	8%	27%****
Pre-coital activities	19%	19%	19%	13%	23%****
Parents divorced	9%	8%	9%	12%	6%***
Live with both parents	89%	90%	87%	85%	91%**
Father finished college	42%	42%	42%	43%	41%

Table 1. Continued

Mother finished college	33%	32%	33%	38%	29%**
Father has a professional job	43%	43%	43%	46%	42%
Mother has a professional job	35%	34%	37%	38%	33%
Mean monthly family income (*SD*)[b]	3.93 (.98)	3.96 (.98)	3.90 (.98)	3.88 (1.09)	3.96 (.90)

[a] Thirteen students did not provide data on gender and one student did not provide data on grade.
[b] Coding for monthly family income: 1 = less than 300 yuan; 2 = 300–500 yuan; 3 = 500–1000 yuan; 4 = 1000–3000 yuan; 5 = 3000–5000 yuan; 6 = more than 5000 yuan.
*$p < .05$. **$p < .01$. ***$p < .001$. **** $p < .0001$.

HIV/AIDS Awareness

As shown in Table 2, 66% of students felt that they knew "a lot or some" about AIDS and 34% knew "little or nothing." AIDS awareness (or perceived AIDS knowledge) differed significantly by age, as older adolescents (e.g., high school students) perceived themselves knowledgeable about AIDS ($p < .0001$). Students' AIDS awareness level differed significantly according to their parents' level of education ($p < .01$), whether their parents had a professional job ($p < .05$) and family monthly income ($p < .0001$). Regarding the question of whether they knew about AIDS being caused by HIV, male gender, higher age, being an only child and higher family SES (i.e., higher parental education, professional job and higher family income) were associated with higher levels of awareness. Among students who knew the cause of AIDS, 16% reported they had been dating, compared with 22% of students who said they did not know the cause of AIDS ($p < .05$). There was no difference in terms of HIV/AIDS awareness by engagement in pre-coital activities (hugging, kissing and foreplay), although more students engaging in these activities thought that they knew "a lot or some" about AIDS.

Table 2. HIV/AIDS awareness among secondary students in China

	How much known about AIDS		Had known about HIV	
	Lots/some	Little/nothing	Yes	No
N (%)	644 (66%)	333 (34%)	479 (49%)	502 (51%)
Mean age (*SD*)	15.31 (1.33)	14.87 (1.40)****	15.24 (1.31)	15.05 (1.40)*
Boys	51%	47%	57%	44%****
High school	66%	47%****	63%	55%*
Han ethnicity	95%	96%	95%	96%
Single child	93%	92%	95%	90%**
Student/club leaders	53%	53%	54%	52%
Excellent/good health	80%	75%	81%	76%
Had allowance	61%	56%	61%	57%
Mostly A's at school	17%	16%	19%	15%
Dating	19%	19%	16%	22%*

Table 2. Continued

Pre-coital activities	20%	16%	19%	19%
Parents divorced	9%	9%	8%	10%
Live with both parents	89%	88%	90%	88%
Father finished college	47%	33%****	52%	33%***
Mother finished college	36%	27%**	40%	26%****
Father has a professional job	46%	38%*	51%	37%****
Mother has a professional job	39%	29%**	41%	30%****
Mean monthly family income (*SD*)[a]	4.03 (.97)	3.74 (.97)****	4.13 (.95)	3.76 (.96)****

[a] Coding for monthly family income: 1 = less than 300 yuan; 2 = 300–500 yuan; 3 = 500–1000 yuan; 4 = 1000–3000 yuan; 5 = 3000–5000 yuan; 6 = more than 5000 yuan.
*p< .05. **p < .01. ***p < .001. ****p < .0001.

Sources of AIDS Information

Sixty-eight percent of the sample reported having received, in the previous month, information about AIDS from newspapers, 61% from television programs, 60% from the health department/physicians and 48% from magazine articles (Table 3). Forty-five percent reported the source as public information/news boards, 40% as radio programs, 36% as books, 33% as bill posts and 31% as school. Twenty-nine percent reported having received the information from displays in shop windows, 24% from their friends and peers or community organizations, 23% from parents or relatives, 14% from displays in the airport, 13% from the AIDS hotline and 12% from displays on a bus or taxi. While more female students received AIDS information from newspapers (71% vs. 65%; p < .05), more male students received it from other channels (e.g., a bus or taxi display, an airport display, the AIDS hotline). More high school than middle school students received AIDS information from newspapers (p<.001) and magazine articles (p<.05), health professionals (p<.05), radio programs (p<.01) and public news/information boards (p<.01).

Thirty-four percent of the middle and high school students identified television programs as the "most reliable source" of AIDS information, and 32% endorsed health department/physicians (23% middle and 38% high school students; data not shown]). Thirteen percent endorsed AIDS hotlines (16 middle and 12% high school students), followed by books (8%) and newspapers (4%). About 2% of students endorsed radio programs, school and family members. Less than 1% of the sample endorsed community organizations, friends/peers, magazines or various public displays. Endorsements were similar between males and females across all sources.

As shown in the lower section of Table 3, about half of the youth said they would ask physicians or turn to an AIDS hotline for AIDS-related questions in the future. More high school than middle school students said they would ask physicians (60% vs. 44%, p < .0001). Forty percent of the sample (47% males vs. 34% females, p < .0001) said they would go to local health departments. One quarter (21% male vs. 29% females, p < .01) said they would ask their parents, and about one tenth said they would ask their friends.

AIDS Knowledge

As shown in Table 4, students responded correctly to 56% of the AIDS knowledge questions. The subcategory with the highest correct response rate was the true transmission mode (87% correct responses), while false transmission mode had the lowest (34% correct responses). Males were more knowledgeable than females in general (57% vs. 54%, p < .01). Males were more knowledgeable about definition/symptoms (61% vs. 54%, p < .0001), false transmission mode (37% vs. 31%,

p < .01) and treatment/prevention (68% vs. 64%, p < .01). Females were more knowledgeable about the true transmission mode (89% vs. 85%, p < .01). Overall, high school students were more knowledgeable than middle school students on all categories, although there was no difference between the two groups' knowledge of definition/symptoms and clinical outcomes.

Table 3. Sources of HIV/AIDS knowledge among secondary school students in China (%)

		Gender		Grade	
Sources	**Overall**	**Male**	**Female**	**Middle**	**High**
Where did you receive HIV/AIDS information in the previous month (%)					
Newspaper	68	65	71*	61	72***
Television	61	61	61	58	63
Health dept./physician	60	59	61	56	62*
Magazine	48	45	50	43	51*
Information boards	45	44	46	39	49**
Radio	40	42	38	34	43**
Books	36	39	34	36	36
Bill post	33	33	32	29	35
School	31	32	29	28	32
Shop window	29	29	29	27	31
Community organization	24	24	25	25	24
Friends/peers	24	24	24	22	26
Parents/relatives	23	21	25	25	22
Airport	14	16	11*	14	14
AIDS hotline	13	16	10*	15	12
Bus/taxi display	12	14	10*	13	12
Whom will you ask if you have a question about HIV/AIDS (%)					
AIDS hotline	55	53	58	54	56
Physician	54	53	54	44	60****
Health department	40	47	34****	37	42
Parents	25	21	29**	24	26
Friends	12	13	12	11	13
School teachers	11	10	12	12	9
Others	5	7	3***	5	5

*$p < .05$. **$p < .01$. ***$p < .001$. ****$p < .0001$.

Table 4. AIDS knowledge (% of correct answers) among Chinese adolescents by gender and grade

		Gender		Grade	
	Overall	Male	Female	Middle	High
AIDS knowledge full scale	**56**	**57**	**54****	**52**	**58****
Definition/symptoms	**58**	**61**	**54****	**56**	**59**
AIDS is caused by a virus (True)	83	85	82	83	84
Person can be infected with HIV and not have AIDS (True)	35	38	32*	31	38*
Person who has HIV can look and feel healthy (True)	58	65	52****	58	58
True transmission mode	**87**	**85**	**89****	**81**	91****
Person with HIV can pass it on during sexual intercourse (True)	95	94	95	90	98****
Pregnant woman who has HIV can give the virus to her baby (True)	95	95	96	93	97**
Sharing needles for drug use with someone who has HIV (Likely)	82	78	86*	74	88****
Having sex with someone who has HIV (Likely)	81	77	85*	73	87****
False transmission mode	**34**	**37**	**31****	**31**	**35***
Working/studying near someone with HIV (Unlikely)	50	49	51	43	54**
Eating in a restaurant where the cook has HIV (Unlikely)	38	40	36	35	40
Sharing plates, fork or glasses (Unlikely)	31	35	28*	30	32
Using public toilets (Unlikely)	26	31	21****	27	26
Being coughed or sneezed on by someone who has HIV (Unlikely)	27	30	24**	26	27
Attending school with a child who has HIV (Unlikely)	45	46	45	40	49**
Being bitten by mosquitoes or other insects (Unlikely)	20	21	18	20	20
Being cared for by a nurse, doctor or dentist who has HIV (Unlikely)	27	32	22***	27	28
Using public swimming pool (Unlikely)	24	29	17****	22	25
Shaking hands with or hugging (Unlikely)	57	59	54	46	65****
Clinical outcomes	**68**	**67**	**68**	**68**	**68**
AIDS can reduce the body's natural protection against disease (True)	94	93	95	91	96**
AIDS can damage the brain (True)	48	43	52**	57	41****
AIDS patients die in a short period of time (Disagree)	65	67	62*	59	79***
Treatment/prevention	**66**	**68**	**64****	**59**	**70****
Drugs available that can lengthen the life of a person infected (True)	71	72	69	70	71
Early treatment can reduce symptoms in an infected person (True)	74	73	75	75	74
Vaccine available that protects a person from getting HIV (False)	53	53	53	41	61****
There is medical cure for the AIDS (False)	78	79	77	71	83****
Using condoms can prevent HIV (Agree)	61	69	53****	51	68****

*$p < .05$. **$p < .01$. ***$p < .001$. ****$p < .0001$.

Table 5. Multivariate analysis (GLM) of AIDS knowledge among adolescents in China

	Gender	Grade	Gender by grade	Income
Multivariate test (*F* for Pillai's Trace)	8.254***	15.352***	1.722	12.252***
Definition/symptoms	15.846***	2.615	4.990*	1.987
True transmission routes	9.962**	40.426***	2.330	42.463***
False transmission routes	6.777**	5.506*	<1	3.668
Clinical outcomes	<1	<1	<1	2.045
Treatment/prevention	8.722**	49.908***	<1	29.954***

*$p < .05$. **$p < .01$. ***$p < .0001$.

Within all subcategories except true transmission mode, there was substantial variation by item in terms of percentage of correct responses. For example, correct responses ranged from 35% to 83% for definition/symptoms, 20% to 57% for false transmission modes, 48% to 94% for clinical outcomes and 53% to 78% for treatment/prevention.

While students were knowledgeable about the true transmission modes of HIV, there were many misconceptions about false transmission modes. More than two thirds of the sample thought (or were not sure) that a person could contract HIV by "sharing plates, fork or glass," "using a public toilet," "being coughed or sneezed on," "receiving medical care from someone who has the AIDS virus" or "using a public swimming pool." Only about one fifth did not think they would be likely to get the AIDS virus from being bitten by mosquitoes or other insects.

General linear model (GLM) analysis conducted on mean scores of five categorical scores of AIDS knowledge (Table 5) confirmed the results of bivariate analysis, with significant main effects of gender (Pillai's $F = 8.254$, $p < .0001$) and grade (Pillai's $F = 15.352$, $p < .0001$). All the bivariate differences in various categories of AIDS knowledge by gender and grade remained similar in GLM analysis. In addition, family income was a significant covariate of AIDS knowledge in GLM.

Discussion

Given the early stage of the HIV/AIDS epidemic in China, awareness and appropriate knowledge may play an important role in preventing further spread of the disease among adolescents and young adults. Data in the current study indicated an overall low and inconsistent level of AIDS knowledge among secondary school students in China. More than one third of students had limited awareness of HIV and AIDS. Consistent with findings from other countries (e.g., Dias et al. 2006; Mahat and Scoloveno 2006), most could identify true transmission modes, but a large proportion held misconceptions about symptoms, activities that did not transmit the virus, treatment and preventive measures.

Consistent with findings in the United States (e.g., DiClemente et al. 1986; Dorman and Rienzo 1988) and other countries (e.g., Tavoosi et al. 2004; Yoo et al. 2005), as well as findings from other populations in China (Li et al. 2008, 2009), secondary school students in China appear to rely on the mass media (e.g., newspaper, television) as their primary source of AIDS information. Likewise, students ranked television and health department/physicians as the top sources they believed provided the most reliable information about HIV/AIDS. However, only 4% endorsed the newspaper as a reliable source, despite about two thirds of the students having reported getting AIDS/HIV information from newspaper articles.

Data in the current study revealed a significant gender difference in AIDS knowledge among secondary school students, with males being more knowledgeable than females, particularly in the areas concerning HIV/AIDS definition/symptoms, false transmission modes and treatment and

prevention. This finding is consistent with studies among college students in China (Li et al. 2004) and other cultures such as Kuwait (Al-Owaish, et al. 1999).

The data suggest that the majority of Chinese secondary school students did not get or did not intend to get HIV/AIDS information from their parents, friends/peers or school teachers. This points to the challenge of discussing sex-related matters or other taboo topics (including HIV/AIDS) with family members, friends and school teachers in Chinese society (Gao et al. 2001; Li 2004).

These data may be limited in their representativeness of the general adolescent population in China, since the sample was largely urban, and about 70% of the Chinese population is rural. The data in the current study suggest that AIDS awareness varies among students based on family socio-economic status, with a higher level of awareness in students from wealthier families. This finding is consistent with that from a previous study, which suggested that HIV/AIDS knowledge was much lower in rural than in urban areas in China (Chen et al. 2004). These findings underscore the importance of HIV/AIDS education among adolescents and young adults in rural areas and from socio-economically disadvantaged families and environments.

The findings in the present study, as one of the few efforts in assessing HIV/AIDS knowledge among adolescents in China, have several implications for HIV/AIDS prevention and education among Chinese adolescents and young adults. First, education and wider health promotion and prevention programs targeting adolescents are needed. While these efforts should include both middle and high school students, clearly programs need to begin at an earlier age level (e.g., middle or even elementary schools). HIV/AIDS education and prevention programs need to provide students with accurate information, particularly in dispelling misconceptions about causal contagion of HIV, as these misconceptions may foster negative attitudes in adolescents toward people with HIV/AIDS (Chen et al. 2004).

Second, the students' low utilization of schools, family and peers in acquiring HIV/AIDS knowledge underscores the great potential of these traditional information channels in HIV/AIDS education and prevention. As current efforts in China in HIV awareness promotion and prevention have largely relied on peer education (Gao et al. 2001) and mass media campaigns (Wu et al. 2007), the mobilization and active involvement of healthcare providers, schools and parents in education and prevention would be critical in fighting the HIV/AIDS epidemic in China.

Third, the knowledge gap between mode of transmission and preventive measures suggests that education and prevention efforts should emphasize the role of condoms and other components of "safer" sex. While a majority (95%) recognized that HIV could be transmitted through sexual intercourse, only about 60% of students agreed that using condoms could prevent HIV. In addition, a substantial global experience supports the observation that mere possession of accurate information does not necessarily lead to behavioural change (Hays and Hays 1992; Mann et al. 1992). Other components of effective prevention, including efficacy building, stigma reduction and skill acquisition regarding preventive measures (e.g., condom use) are needed, beyond information dissemination. Finally, the discrepancy between levels of utilization and trust of mass media (e.g., newspapers) among adolescents warrants the attention of educators and policy-makers. The role of mass media in AIDS awareness promotion in China needs to be improved, as mass media serves as one of the main channels for the disseminating AIDS knowledge among adolescents and young adults.

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Exploring the Meaning of Childhood Disability: Perceptions of Disability among Mothers of Children with Disabilities (CWD) in Kuwait

Sudha R. Raman, PT, Department of Epidemiology, Gillings School of Global Public Health, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, USA

Shilpa Mandoda, MSc, Research Associate, Department of Physical Therapy, University of Toronto, Toronto, Ontario, Canada

Laila Kasim Hussain, PT, Physiotherapist, Department of Paediatric Physiotherapy, Physical Medicine and Rehabilitation Hospital, Kuwait

Niamh Foley, PT, Physiotherapist, Fawzia Sultan Rehabilitation Institute, Kuwait

Elham Hamdan, MD, Medical Director, Fawzia Sultan Rehabilitation Institute, Kuwait

Michel Landry, PT, PhD, Assistant Professor, Department of Physical Therapy, University of Toronto, Toronto, Ontario, Canada, Fawzia Sultan Rehabilitation Institute, Kuwait

Correspondence may be directed to: Michel D. Landry, Department of Physical Therapy, University of Toronto, 160–500, University Avenue, Toronto, Ontario, Canada, M5G 1V7, Fax: 416-946-8562, Email: mike.landry@utoronto.ca

Abstract

The purpose of this exploratory research was to examine perceptions of mothers with children with disabilities (CWD) in Kuwait in order to understand the meaning of disability from their perspective and to explore the extent to which such perceptions influence rehabilitative services that their children receive. Ten semi-structured interviews were conducted with mothers of CWD receiving services at a large pediatric facility in Kuwait. Four themes emerged from the interviews: (1) mother's perceptions of disability, (2) mother's extended caregiver role, (3) religious beliefs as a coping strategy, and (4) perception of rehabilitation services. Our findings suggest that despite a traditional acceptance

of disability as divine intervention or a challenge sent to them by God, mothers were motivated to maximize rehabilitation services in order to improve the functional capacity of their children. Kuwaiti mothers may hold both the fatalistic view of disability, and the belief that the course of disability can be altered through a rehabilitative intervention, in tension. An appreciation of this phenomenon might move toward a rehabilitation delivery model that integrates and harmonizes such beliefs.

Background

The World Health Organization (WHO) estimates that 10% of the global population experiences some form of disability, including approximately 200 million children (2008). In the not-so-distant past, disability was understood to be the relative inability to perform or accomplish tasks that one's peers could perform. Terms such as invalid were grounded in this pejorative and depreciatory understanding (Brown et al. 2000; Gething 1992; Miller 1996). Over time, however, the conceptualization of disability has evolved. Generally, people with disabilities are now considered to have varying degrees of ability measured along a multidimensional continuum (Masala and Petretto 2008; Wahl et al. 2009; Wiart and Darrah 2002;). At one end of the continuum, a person may have no physical, mental or emotional limitations, while at the other end, physical, mental or emotional factors can create important limitations in performance. The International Classification of Functioning, Disability and Health (ICF) defines disability as an umbrella term that characterizes all impairments, activity limitations and participation restrictions relating to the body, the individual and society (WHO 1980, 2001). Although there are academic debates regarding the ICF model (Cieza et al. 2009; Rauch et al. 2009; Wynia et al. 2009), it is likely that parents of children with disabilities perceive, define and contextualize disability in multiple ways. Beyond academic definitions, the importance of understanding parents' perceptions of disability is critical in order to optimize the delivery of health services within global, regional and local health and social care communities (Armstrong and Ager 2005; Gan et al. 2008; Law et al. 2003). This understanding may in turn contribute to functional improvements for the individual and, by extension, further the actualization of human rights in all persons with disabilities.

It has been suggested that perception of disability may be a pivotal determinant of the health services sought by mothers of children with disabilities (Danesco 1997; Diken 2006). In other words, both biomedical and traditional perceptions, attitudes and beliefs about disability may influence a mother's care-seeking behaviour. For instance, a Turkish study by Diken (2006) reported that mothers who perceived their child's disability as the result of a traditional cause were more likely to seek a traditional intervention, whereas mothers who perceived a biomedical cause were more likely to pursue formal medical services. Furthermore, it has also been reported that individuals from many cultures hold biomedical and traditional beliefs simultaneously regarding the nature and causation of disability. This may lead them to pursue multiple concurrent treatments (Danesco 1997; Diken 2006; Hosain et al. 2005).

Mothers' perceptions of disability may also be profoundly influenced by attitudes of their family and community. In a case study from the United States, researchers reported that mothers were more likely to feel embarrassed and guilty about their child's disability if they themselves felt that people with disabilities were devalued and discriminated against in their community (Green 2003). Additionally, the same research group found that mothers who experienced a great deal of stigma related to their child's disability reported a higher burden of care for their child, were much less likely to interact with peers and were less likely to investigate age-matched interactions for their children (Green 2003). Members of the current team of investigators have been involved in exploring the perception of disability among mothers who have a child with a disability (CWD) in different countries in order to explore the links between perception of disability and health-seeking behaviours. For instance, in a study by Maloni et al. (2010), the authors concluded that understanding mothers' perceptions of disability and treatment, and the myriad of factors that influence those perceptions, provides valuable knowledge to assist in planning and delivering family-centred rehabilitation services for CWD. In a follow-up study, Daudji et al. (in press) expanded the research agenda

by investigating perceptions among recent South Asian immigrants to Canada and concluded that in this population, mothers' perceptions of their child's disability were influenced both by traditional cultural notions of disability and by those imposed on them through institutional and societal norms within their new country. To help these mothers achieve a positive and realistic frame of reference for their child's disability, Daudji et al. suggested that healthcare providers should play an important role in advocating for access to social supports and helping mothers set achievable goals for their child. Rehabilitation has a central role in helping mothers understand the nature of their child's disability and how to manage it. Ultimately, an understanding of parental perception is thought to improve the long-term social and educational opportunities for CWD.

The purpose of this current study was to expand upon previous research and examine mothers' perceptions of CWD in Kuwait in order to understand the meaning of their perception of disability and to explore the extent to which such perceptions influence the rehabilitative services their children receive. In this study, Kuwait serves as a unique example of a society with a strong familial and religious-based organization that has also recently experienced rapid development and change from the tremendous wealth generated from the petroleum industry.

Methods

A descriptive qualitative design was employed to address the research objective. Approval for the study was obtained through the Kuwaiti hospital's senior management and the research ethics process where the study took place.

Identification and Recruitment of Participants

We used convenience sampling to identify participants. They were included if they were (1) a mother of a child with a disability attending rehabilitation at a large pediatric facility in Kuwait City, and (2) able and willing to participate in a 30-minute face-to-face interview in June or July 2009. A hospital staff member not involved in patient care recruited mothers who met the inclusion criteria. Potential participants were told about the study objective, informed that their participation was completely voluntary, that all information would remain confidential, and that they would be free to withdraw at any time without consequence. They were also assured that choosing not to participate would in no way affect their child's treatment. If the mother was interested in participating, the staff member scheduled an interview session with the research team. If she remained interested after this first information session with the research assistant, an interview was scheduled at a convenient time. The potential risk of discomfort at disclosing personal information regarding mothers' experiences with a CWD was discussed during the first contact with the research assistant and again at the time of the informed consent process that preceded each interview.

Primary data was collected through semi-structured face-to-face interviews. The interview schedule consisted of 21 structured open- and close-ended questions. Trained research assistants conducted all 10 key informant interviews at the facility between June and July 2009. All interviews were conducted in Arabic, and once the interview was completed, the research assistant immediately transcribed it into an MS Word document. Each interview was then translated into English by the same research assistant. A second research assistant who had not transcribed the interviews reviewed each of the audio recordings and subsequent transcriptions in order to ensure that the qualitative data was accurately transcribed and translated.

Data Analysis

Transcribed interview data were entered into a qualitative data analysis software package (NVivo 2.0) for systematic coding. The research team then performed content analysis to identify themes that emerged from the interviews. Content analysis, or qualitative description, has been reported as useful when the description of phenomena is desired (Pope et al. 2000). The identified themes were based on informants' collective perceptions and experiences relevant to the issues being explored in the study. Once transcripts had been coded, reports were generated so that the research team

could analyze the data according to the research objectives. The team met regularly from August to October 2009 to share impressions, develop main themes and discuss alternate interpretations.

Results

A total of 10 mothers consented to participate in the study (Table 1). Their ages ranged from 28 to 38 years. Three were not familiar with the medical term for their child's disability, whereas the others reported that their child was diagnosed with one the following: cerebral palsy (n = 3), congenital defect of the pelvis (n = 1), hemiplegia (n = 1), quadruple paralysis (n = 1) and stroke (n = 1).

Four themes emerged from the data: (1) mother's perceptions of disability, (2) mother's extended caregiver role, (3) religious beliefs as a coping strategy, and (4) perception of rehabilitation services.

Table 1. Participant demographics

Participant number	Age of mother (years)	Mother's description of disability	Sex of child	Total number of children in family
1	33	Cerebral palsy	F	1 (and pregnant)
2	30	Congenital defect in pelvis	M	6
3	35	Cerebral palsy	F	2
4	30	Unidentified	M	5
5	31	Hemiplegia	F	5
6	29	Quadruple paralysis	M	2
7	38	Stroke	F	2
8	29	Unidentified	M	3
9	28	Cerebral palsy	F	2
10	28	Unidentified	F	4

1. Mother's Perceptions of Disability

In general, participants felt uncomfortable with the word *disabled* and believed it portrayed their child negatively. From their perspective, *disability* was synonymous with having an incomplete child. Despite their discomfort with this term, however, it may be important to note that the mothers continued to use it throughout the interviews. Many felt that even though their child was disadvantaged in some ways, he or she was gifted in others that "normal" people were not. For instance, one mother stated, "…in my opinion a disabled person has achievements and more creativity than normal people do." The belief that CWDs possessed special and unique features that surpassed their non-disabled peers was a perception all participants shared.

Participants also believed that their families and community had preconceived, negative perceptions about individuals with disabilities. The mothers reported that words such as *pity* and *sympathy* were often used to describe the general community's perception of their CWD. They felt that although their child had many abilities, their families and communities perceived that he or she was fully incapable and needed constant help. One participant noted how members of the community were more sympathetic toward her child once they were aware of her disability, but she feared that

that this "over sympathy" would further segregate her CWD from other children in the community. According to this mother,

> Sometimes they [society] over-sympathize with them [CWD], which I think affects disabled people and makes them feel that they are not normal. In my community they feel sympathy towards her because she is not capable like other kids.

Participants remarked that the community should not "overly sympathize" with their disabled child or give him or her special treatment. Treating the child as "normal" would help him or her integrate, and feel more integrated, in society. For example, one mother with a child with cerebral palsy asserted that,

> We shouldn't sympathize with disabled people, so that they doesn't feel incomplete. I treat her like a normal child, I talk to her even though she hasn't started speaking yet … I don't want her to get used to special treatment.

Despite the positive perspective on the abilities of CWD, and the suggestion that community members should not demonstrate overt sympathy for them, a minority of participant mothers themselves expressed a deep sense of internal sympathy for their child regarding the challenges that he or she will face in the future. For instance, one mother revealed, "I feel devastated when I see other kids her age playing while she's sitting next to me." These dual perspectives outline a possible dissonance between outward and verbal perspectives on disability and the internal, more intimate perspective about the child.

2. Mother's Extended Caregiver Role

Participants reported giving greater attention to their CWD than to their non-disabled children, because they felt the child had greater needs. A large amount of the mothers' time was dedicated to caring for their child, meeting special needs and fulfilling operational tasks such as taking the child to medical and rehabilitation appointments. All participants said they dedicate time on a daily or weekly basis to attend appointments with their child. The following two quotations reflect this perceived extended caregiver role:

> When I discovered his disability, I thought that I need to concentrate more on my child and their needs. The normal person can take care of himself but he needs more care from me.

> I need to take care of her a lot more than before [she was disabled]; when she had appointments I didn't go, but now I must take her to all her appointments.

Participants expressed a great deal of concern regarding their feelings of exhaustion and stress secondary to their extended caregiver role. They found it difficult to balance their time between professional careers and their traditional role in the family unit, including caring for their children. The perceived inability to fulfil a traditional role within the family due to the extended caregiver role for the CWD had created stress within their family units over the years, and they feared that this would become even more challenging in the future. The following two quotations represent the perspective of increased burden of care associated with the mothers' extended caregiver role.

> I'm always busy. Once I finish my work I go home directly and always stay with her, and I don't leave her unless there is something important; otherwise. I'm always with her.

> My colleagues at my work don't understand what I'm going through and that I have to leave my work to bring her to here [the rehabilitation centre] and then go back to work again. Having a disabled child is different than having a normal child.

The mothers' caregiving role was, in general, described as being extensive and appeared to cause feelings of distress in all of them.

3. Religious Belief as a Coping Strategy

All participants in the study expressed very strong religious beliefs and held that these beliefs provided a strategy that allowed them to cope with their personal perspective on disability and their extended caregiving role. All mothers reported that it was "fate" or "divine intervention" that God, or Allah, chose them to care for a CWD. They believed that their CWD was given to them for a particular reason. For instance,

> Some people when they know that their child is disabled, they say "why did Allah let this happen?" But I thought that Allah did this for a reason, and he did this because he loves me.

It was common for participants to perceive that their child's disability was the will of God, and they expressed gratitude toward him numerous times during the interview. For instance, one participant stated, "If Allah wants her to be like this permanently, then I can't do anything to change it. Thanks to him anyway." For all participants, grounding the explanation of disability from a fatalistic perspective appeared to provide a context for interpreting and coping with the internal and external issues that surround the CWD. Even those who specifically described their CWD's medical diagnosis held this view.

In additional to this traditional view of disability, a minority of participants also perceived that their child's disability was given to them as a "test from him [Allah], to see how patient I am." One recited a prayer from the Quraan during the interview, which translates to, "Thanks to Allah, who is the only one that we thank when something wrong happens." This subgroup of three participants believed that having a CWD was as a challenge or test sent by God, and that if they could overcome this challenge, it would strengthen their faith. For instance,

> I ask Allah to make him better a lot and sometimes when I feel that there is no hope my faith helps me not give up … thanks to Allah I feel that my faith has increased, now I'm stronger than before.

Based on these perspectives, although all participants shared a fatalistic perspective on their child's disability, a minority appear to describe their circumstances as a challenge, or mission. They believe that they must overcome this challenge and in doing so their faith will be strengthened by God. Although our qualitative data do not allow us to establish an empirical link, it was suggested that the group who perceived the disability as a challenge sent by God may be more motivated to alter the course of the disability through rehabilitation.

Despite the underlying perceptions, a strong religious faith among both groups kept participants hopeful about their child's progress and future potential. As will be more fully described in the next section, all mothers expressed tremendous willingness to focus on altering the course of their child's disability through rehabilitation services.

4. Perception of Rehabilitation Services

Overall, participants found that rehabilitation services had improved their CWD's condition. They described the level of care from the centre where they were receiving rehabilitation services as "excellent" and that staff were very helpful; some reported being surprised at how friendly and knowledgeable the staff were toward them. Although there was no expectation of a cure for the disability, all participants were pleased to have their child involved in rehabilitation as a way of providing improvement in their function.

Despite the overall positive experience with rehabilitation, participants reported a series of barriers, categorized into two main areas: (1) a shortage of rehabilitation staff, and (2) difficulty

with follow through of prescribed home-based therapeutic regimes. Although we discuss these two items separately below, they appear to be linked in many ways.

First, participants felt that the facility had long wait times and was becoming overcrowded, thus limiting the length of scheduled appointment times. Staff shortages were also observed and, while rehabilitation resulted in improvements to their child's physical abilities, participants felt that a greater number of appointments would yield better results. They wanted more frequent and intense rehabilitation, and perceived that there was a causal link between disability and frequency of treatment. In other words, for them, more rehabilitation translated in improved function and minimization of disability. For example, according to one mother,

> The centre is excellent and the staff is very nice.… I want him to be better, there [are] a lot of patients who wait for three or four months to get the treatment started. I'm waiting for an occupational therapist to call to me to set up an appointment. They need more staff.

Another participant reflected a similar perspective when she reported,

> [Therapy] is really useful, but the problem is that there are not enough appointments; for example, she only gets eight sessions in hydrotherapy; then it stops. She just had a surgery and they gave her eight sessions of hydrotherapy and 1.5 to 2 months of physical therapy. After that they gave her a break because they have a lot of patients and they are under-staffed, not enough of them to take care of all the patients.

Second, participants expressed difficulty in carrying out the prescribed rehabilitation exercises and also reported that this process was made worse due to lack of co-operation from their children. Participants described scenarios where the rehabilitation providers asked them to follow through with home programs with their child, between sessions at the pediatric facility. The mothers described not fully understanding the home program and expressed concern that they would not do the home exercises correctly. Ultimately, they did not necessarily see this as their role and appeared to rely heavily on the rehabilitation provider and the hospital for the delivery of services. The following quotation exemplifies this perspective.

> I went to all of her appointments to know if she is getting better or not, and the physical therapist told me that I have to do two hours of exercise with her daily, but it's hard to do the exercises at home … then they [physical and occupational therapists] told me to do the exercises to her for three months, but it was difficult to do it at home and my daughter didn't respond well with me. Now I applied for her to be treated abroad, even though her case can be treated [here in Kuwait] but I'm afraid that it may get worse.

All mothers expressed the belief that rehabilitation services have, and would, benefit their children. The interpretation is that more rehabilitation services provided at the hospital would yield better outcomes. The role of the mothers, and by extension their families and communities, was minimized along this rehabilitative trajectory. As such, there was concern about the frequency of service delivery and the mothers' ability to provide these services through home-based programs.

Discussion

Participants perceived that their child was capable of many activities and that their disability was not a limitation to their future potential. We found in this study that mothers were able to see beyond their child's physical limitation to creative strengths that were not present in other children. The community in which they lived, however, did not always recognize these qualities. Although we found no related literature based in Kuwait, research from the United Arab Emirates, a neighbouring country in the Arabian Gulf region, reported that families with disabled children perceive disability

to be humiliating and shameful (Crabtree 2007). However, Crabtree (2007) suggested that although stigma against people with disabilities remains prevalent in Middle Eastern and Gulf countries, it has in many ways improved over time. Mothers in this study seemed to echo these progressive views by indicating that Kuwaiti society does indeed exert negative influences, but rather than from a foundation of humiliation and shame as suggested by Youssef (1994), the negative influence may be due to being "overly sympathetic" or patronizing to the child and his or her challenges. While perceptions are slow to change, and further investigations are warranted, it appears there may be an ongoing evolution of the perception of disability in Kuwait.

It also appears that the age and gender of a disabled child may have influenced the mother's perception. For instance, Khamis (2007) indicated that levels of stress in parents decreases as the child gets older. At the time of data collection, no information was gathered on the present age of the disabled child; however, interviews indicated that mothers found out about their child's disability at or before birth, or at six months or one year of age.

A majority of the mothers were aware of the medical condition underlying their child's disability, but simultaneously believed that God had chosen them to take on the responsibility of raising a CWD. Most believed that their child was given to them by divine intervention, while a sub-sample also thought that their CWD was sent to them a test or challenge from God. Parents in many cultures have often depicted their children's disability as a result of fate, divine punishment or intervention due to peculiar events, and other religious or socio-cultural beliefs (Danesco 1997). The role of religion and the will of God have been reported in a previous study (Daudji et al. in press), where mothers believed that this path had been chosen for them and that they were given this gift by God because of their personal resources, knowledge and strength, resources that are necessary to be responsible for a child with a disability. Some authors have argued that attributing some responsibility to God also allows a mother cope with the stresses associated with having a CWD (Balasundaram 2007; Burker et al. 2005; Rippentrop et al. 2005; Treloar 2002). Moreover, attributing responsibility to God has been found in previous studies. Chang and McConkey (2008) studied the perceptions of 117 Taiwanese mothers and fathers in Tapei, where the population is predominantly Buddhist. The authors revealed that mothers felt social isolation and encountered social stigma from the community. The mothers felt they could not attend the temple any more because they had been told that the disability was a result of their having sinned. Similar findings were also found Huang et al. (2009), where Taiwanese mothers believed their child was disabled because of his or her bad karma from a previous life. Croot et al (2008) interviewed 16 Pakistani parents and one grandparent in the United Kingdom. Parents attributed their child's disability as a gift or a test from God, or a curse from evil spirits. Others believed they were chosen to have a child with a disability for some divine purpose unknown in this life. Some also thought it was a punishment from God for their wrongdoing.

In this study, we found a strong link between perception of disability and religious beliefs, suggesting that that concept of disability is framed from a spiritual perspective, not according to biomedical frameworks and their components, such as the ICF model.

Sen and Yurtsever (2007) suggested that mothers reported having difficulty in balancing their worklife and caring for a CWD, and Brandon (2007) reported that a mother raising a CWD spent less time on average on personal care and recreation than other mothers. More time was spent socializing, since they found support in the shared experience of other mothers of children with disabilities. It may also be important to note that the same study reported that a father's personal care time per week was not affected as greatly as the mother's, supporting our finding of mothers' extensive responsibility their children. Mothers' responsibilities and associated stresses were mitigated in part by religious beliefs about the value of their situation. Respondents in our study mentioned receiving support from family, friends and the community; this was also reported by Daudji et al. (in press) and Maloni et al. (2010). Mothers did not mention the role of their husbands in caregiving for their child, suggesting that, at least in this convenience sample, mothers had the primary responsibility for caring for their child and ensuring they attended rehabilitation appointments. Although community

perceptions and reactions to disability were noted as potentially problematic, the overall impression from these mothers was that their community and religious background gave them support and helped them to cope with the responsibility.

This study sought to explore how Kuwaiti mothers of CWD perceive disability and, as such, provides insight regarding the impact that these perceptions may have on the care they seek for their children. Our data now provide an initial framework from which to consider how these views may influence what services Kuwaiti mothers seeks for their children. For instance, we have noted that there may be a different understanding of the role of God (e.g., some believe it is fate; others go further and interpret their CWD as a test or challenge they must overcome) in explaining how and why these mothers had child with a disability. Despite their fatalistic views, however, mothers perceived that rehabilitation services altered the trajectory of disability. On the other hand, despite the positive view of rehabilitation services, it is not clear that the participants accept that they, their families and their communities have a role to play in the rehabilitation process. They expressed concern over the insufficient amount of rehabilitation their child was receiving and articulated that they were unclear on how to follow through with home-based rehabilitation programs. These findings can provide rehabilitation health professionals with insight into the experiences that mothers in Kuwait face. Outside Kuwait, the experiences and cultural beliefs may be useful to health professionals who treat Kuwaitis who have migrated to other parts of the world, as well as populations with strong similar religious beliefs.

Implications for Rehabilitation Delivery

Irrespective of the ways in which participants conceptualized disability, their view that rehabilitation is valued and capable of making an impact indicates their readiness to access the services. However, the extent to which these mother can, or will, actively participate in their children's rehabilitation remains unclear. What has emerged from this research is that the mothers who participated in this study perceive themselves as having little responsibility in the delivery of services at home. This dichotomy between strongly supporting rehabilitation on one hand, and interpreting a relatively minor role for themselves within the rehabilitation process on the other, may highlight an important gap along the rehabilitative trajectory. Mothers perceive a large and important role as the extended caregiver but do not necessarily interpret rehabilitation as a process that is integrated into activities of daily living. It is generally common practice in pediatric rehabilitation to create home-based programs in order to amplify and sustain the gains made in the application of rehabilitation.

The persistence of this belief should encourage clinicians to focus on addressing the institutional barriers or personal factors that prevent mothers from carrying out their home programs. Kerem Günel (2009) and King et al. (2004) have suggested that adopting a client- and family-centred approach, by including the family in clinical decision-making regarding the rehabilitative process with the CWD, offers the greatest opportunity for functional improvement. Thus, greater involvement of the individuals who surround the CWD offers a greater potential for success. Pediatric rehabilitation approaches that provide detailed education about home exercise programs, behaviour management and feedback about parents' techniques will increase confidence and adherence and will reinforce the impact of rehabilitation on the child's functional status. More broadly, rehabilitation providers can also respond to these findings by linking parents with other services that may help in the management of daily life (e.g., support groups, play groups, respite services). If these services are lacking, therapists are in an ideal position to advocate for additional supportive services for their patients.

Conclusions

This study contributes valuable information about the ways in which Kuwaiti mothers perceive disability, their children, their communities and rehabilitation services. This research reaffirms the role that religion plays in mothers' understanding of their child's condition and their ability to cope with extensive caregiving demands. For rehabilitation providers, understanding that the integration of religious beliefs with rehabilitation practices is possible will be an important part of expanding a

family-centred approach to care delivery. Problematic community perceptions about disability are modifiable through education, as it is part of a rehabilitation provider's role to educate both family members and the larger community about the nature and abilities of CWD. Lastly, healthcare professionals can aid in the process of mainstreaming CWD and their families into the community, as the mothers noted that increased understanding of disability in the greater community would facilitate integration of their children.

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Appendix: Interview Guide

Section 1: Personal/Background Information

1.1 What is your country of birth?
1.2 How many children do you have?
1.3 Do you have any other children with disabilities?
1.4 How often do you attend rehabilitation with your child?

Section 2: Perception of Disability

2.1 How did you find out about your child's disability?
2.2 When did you find out that your child had a disability? Who informed you?
2.3 Do you know the name of the medical term of what disability your child has?
2.4 How did you feel when you found out that your child had a disability?
2.5 How has your role changed since _____(child's name) has come into your life?
2.6 How does religion impact how you feel about your child's disability?
2.7 What do you believe caused the disability in your child?
2.8 What does disability mean to you?
2.9 How does your community view disability?
2.10 How does your community view your child's disability?
2.11 How does the rest of you family view your child's disability?
2.12 Do you have support from your family or the community?

Section 3: Rehabilitation Services

3.1 What made you decide to pursue rehabilitation treatment for your child?
3.2 How did you hear about the [name of hospital]?
3.3 How do you feel about the services here [name of hospital]?
3.4 What are other treatments (medical/non-medical) have you used to treat your child?

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