

Ethnic specific recommendations in clinical practice guidelines: a first exploratory comparison between guidelines from the USA, Canada, the UK, and the Netherlands

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Qual. Saf. Health Care 2003;12;353-358 doi:10.1136/qhc.12.5.353

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ORIGINAL ARTICLE

Ethnic specific recommendations in clinical practice guidelines: a first exploratory comparison between guidelines from the USA, Canada, the UK, and the Netherlands

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See editorial commentary, pp 328-9

Qual Saf Health Care 2003;12:353-358

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Accepted for publication 19 January 2003

Objectives: To investigate whether clinical practice guidelines in different countries take ethnic differences between patients into consideration and to assess the scientific foundation of such ethnic specific recommendations

Design: Analysis of the primary care sections of clinical practice guidelines.

Setting: Primary care practice guidelines for type 2 diabetes mellitus, hypertension, and asthma developed in the USA, Canada, the UK, and the Netherlands.

Main outcome measures: Enumeration of the ethnic specific information and recommendations in the guidelines, and the scientific basis and strength of this evidence.

Results: Different guidelines do address ethnic differences between patients, but to a varying extent. The USA guidelines contained the most ethnic specific statements and the Dutch guidelines the least. Most ethnic specific statements were backed by scientific evidence, usually arising from descriptive studies or narrative reviews.

Conclusion: The attention given to ethnic differences between patients in clinical guidelines varies between countries. Guideline developers should be aware of the potential problems of ignoring differences in ethnicity.

ver the past 20 years clinical practice guidelines have become an increasingly popular tool for implementation of scientifically based clinical information to improve the quality of health care. Many countries have produced such guidelines, mainly via specialist and/or general practice organisations. As defined by the Institute of Medicine (USA), clinical practice guidelines are "systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances". These statements should be based on the best available scientific evidence and practical knowledge; however, the increasing number of clinical guidelines has stimulated discussion about their value. Each

An area that has received less attention in such discussions is the "specific clinical circumstances". Besides the disease specific characteristics, the "specific clinical circumstances" usually refer to the age and sex of the patient. However, with the increase in migration to western countries during the last 50 years, these western countries have increasingly become more multicultural and physicians are increasingly confronted with patients from diverse ethnic groups. In some of these groups particular diseases can be more prevalent or more severe, and this may also determine the patient's clinical circumstance.7-10 Ignorance of ethnic differences between patients could lead to inferior quality of care for ethnic minorities. Many potentially avoidable procedures such as amputations, avoidable hospital admissions and readmissions, avoidable pain from cancer, untreated disease, and deaths are associated with a lower quality of care for ethnic minorities.11 12 The question as to whether ethnicity should be a specific clinical circumstance systematically taken into consideration in clinical practice guidelines has not yet been fully addressed. The aim of the present study was to investigate whether clinical practice guidelines in different countries take ethnic differences between patients into consideration, and

the scientific basis and strength of such ethnic specific recommendations

METHODS

The clinical guidelines for three prevalent and chronic health problems—type 2 diabetes mellitus, hypertension, and asthma—used in four western countries were examined between 2000 and July 2001. These particular health problems were selected because of the relatively high impact of these diseases in western countries and because of the expected differences between members of different ethnic groups. For these three health problems primary care guidelines from national organisations in the USA, Canada, the UK, and the Netherlands were analysed (n=13; one guideline per disease from each country except the Dutch asthma guidelines which consisted of two separate guidelines, one for diagnostics and one for treatment). The USA guidelines were developed by the National Heart, Lung and Blood Institute (asthma 1997; hypertension 1997) and the American Diabetes Association (2001),13-15 the Canadian guidelines by the Canadian Medical Association (asthma 1999; hypertension 1999; diabetes 1998), 16-18 the British guidelines by the British Thoracic Society (1997), the British Hypertension Society (1999), and Diabetes UK (2000),19-21 and the guidelines used by Dutch general practitioners (GPs) were developed by the Dutch College of General Practitioners (asthma 2001; hypertension 1997; diabetes 1999).22-25 Because some guidelines covered the whole spectrum of care and others focused on primary care only, we studied only the primary care sections of the different guide-

Each guideline was carefully examined (by DRM) and any ethnic specific statement and/or recommendation made was marked and noted. This procedure was repeated (by MAB) and an inter-rater agreement was calculated. Consensus was

Box 1 Categories of strength of evidence of statements in clinical guidelines (developed by the North of England evidence-based guideline development project)

la: Evidence from meta-analysis of randomised controlled trials

Ib: Evidence from at least one randomised controlled trial lla: Evidence from at least one controlled study without randomisation

Ilb: Evidence from at least one other type of quasiexperimental study

III: Evidence from descriptive studies, such as comparative studies, correlation studies and case controlled studies

IV: Evidence from expert committee reports or opinions or clinical experience of respected authorities, or both.

IV*: Narrative reviews

Narrative reviews could not be properly categorised into the categories of the North of England evidence-based guideline development project. For this reason we added IV to the existing categories.

reached in all cases of disagreement. The identified statements were then organised into the following coherent themes:

- epidemiology (including aetiology);
- diagnostics (including screening);
- treatment (including therapy);
- patient education;
- (content of) medical record;
- (overall) cultural sensitivity.

The statements were designated either as merely empirical information/facts or as specific recommendations in the guidelines. The underlying scientific evidence for each ethnic specific statement was collected by checking all the references mentioned in the guideline for the specific statements; by reading the evidence, the strength of the evidence was then graded according to an adjusted version of the schemes of the North of England guideline development project (box 1).²⁶

RESULTS

The overall inter-rater agreement was good. Forty seven segments of text regarding ethnic differences were identified in the guidelines, of which 42 were identified by both authors (inter-rater agreement: 89%). All 47 were included in the analysis.

Ethnic specific information in diabetes guidelines

Table 1 gives the analysis of the diabetes guidelines. All four guidelines made an empirical statement about a higher prevalence of diabetes among certain ethnic groups. The US, Canadian and, to a lesser extent, the UK and Dutch guidelines had some additional statements (related mainly to diagnostics/screening) about the consequences of this higher prevalence. The statements in the Canadian guideline were presented in a separate section dedicated to diabetes among their aboriginal population, except the recommendation to obtain insight into the ethnic and cultural influences on the nutrition of the patient.

Scientific basis of ethnic specific information in diabetes guidelines

For diabetes the different guidelines used different sources of evidence (research papers) for their ethnic specific statements. The evidence was mainly type III (descriptive) prevalence studies and all addressed their own national situation.

Ethnic specific information in hypertension guidelines

Table 2 presents the analysis of the hypertension guidelines. The Dutch guideline contained no ethnic specific statements, the Canadians had only one such statement (albeit an important one), and the US and UK reported more extensively (in separate paragraphs) about ethnic differences. The guidelines made empirical statements about (1) a higher prevalence, more severe hypertension, and a higher risk of complications in certain ethnic groups; (2) the difference in response to pharmacological treatment; and (3) the higher sensitivity to dietary salt restriction among black subjects. These empirical statements led to different treatment recommendations in the respective guidelines.

Scientific basis of ethnic specific information in hypertension guidelines

For epidemiology the evidence was primarily from type III (descriptive) studies or narrative reviews, while the evidence for the differential response to pharmacological treatment was mainly from randomised controlled trials. One study (type Ib) was used as evidence in both the US and UK guidelines.

Ethnic specific information in asthma guidelines

In the asthma guidelines (table 3) one empirical statement about the ethnic variability of lung function was found in both the US guideline (in a separate paragraph) and in the Dutch guideline. The US guideline also stressed the importance of a culture sensitive approach to the patient. The Canadian guideline made no ethnic specific statements, and the UK guideline had only one minor remark about the failure of attending education programmes.

Scientific basis of ethnic specific information in asthma guidelines

Almost all evidence in the guidelines for asthma were based on type III (descriptive) studies.

DISCUSSION

The results of this study show that clinical guidelines from the four western countries do contain ethnic specific information and recommendations, but to a varying extent. The Dutch guidelines contained only a few empirical facts and only once made an additional specific recommendation based on these facts. The other three guidelines added more recommendations to the empirical facts, only for hypertension in the case of the UK, only for diabetes in the case of Canada, but for all three health problems in US guidelines. The US guidelines therefore gave the most attention to ethnic differences by presenting empirical facts as well as formulating specific recommendations

Because most of the statements about ethnic differences in the different guidelines were based on differences in epidemiology (prevalences), the scientific evidence used consisted mainly of descriptive studies or narrative reviews and addressed their national situation. The US guidelines tended to use more evidence.

This is a first exploratory study of the attention given in clinical practice guidelines to ethnic differences. We focused on guidelines from only four western countries and thereby narrowed our scope considerably. Although our comparison is useful, it would be interesting to broaden it in further research by including guidelines from other countries with a relatively large group of subjects from ethnic minorities.

It is difficult to give an explanation for the difference in focus on ethnic differences in the guidelines found in this study because the guidelines are produced and used in the complex environment of a healthcare system. Ethical, economic, legal, political, and cultural aspects are involved which vary in the different countries. Because of historical developments, countries may have their own specific way of

Category	Type of statement	Statement about ethnic differences	Country	Evidence	Strength
Epidemiology	Empirical	Higher prevalence	USA	Fujimoto (1987) ²⁷	III
	•			Zimmet (1992) ²⁸	IV*
				Harris (1995) ²⁹	IV*
			CAN	Dean (1992) ³⁰	III
				Delisle (1993) ³¹	III
				Fox (1994) ³²	III
				Harris (1997) ³³	III
				Harris (1997) ³⁴	III
				Dean (1998) ³⁵	IV
				Tuomilehto (1992) ³⁶	IV
			UK	No reference	_
			NL	Berghout (1995) ³⁷	III
				Bongers (1995) ³⁸	III
				Querido (1995) ³⁹	III
				Reitsma (1995) ⁴⁰	IV*
Diagnostics	Recommendation	Testing for diabetes at younger age or more frequently	USA	Harris (1995) ²⁹ †	IV*
			CAN	No reference	-
	Recommendation	Screening if patient is 45 years (or older) and member of ethnic	NL	Berghout (1995) ³⁷ †	III
		group		Bongers (1995) ³⁸ †	III
				Querido (1995) ³⁹ †	III
				Reitsma (1995) ⁴⁰ †	IV*
	Recommendation	Aggressive screening for complications	CAN	No reference	-
	Recommendation	Community based screenings programs should be established	CAN	Delisle (1993) ³¹ †	III
				Harris (1997) ³³ †	III
	Recommendation	Primary prevention programs initiated by Aboriginal communities	CAN	Delisle (1993) ³¹ †	III
		should be encouraged.		Harris (1997) ³³ †	III
	Recommendation	In identifying patients the higher prevalence should be remembered	UK	No reference	-
Patient education	Recommendation	Nutrition recommendations should consider cultural and ethnic	USA	No reference	-
		background	CAN	No reference	-
Medical record	Recommendation	Medical history and management plan should consider important cultural factors	USA	No reference	-
Cultural sensitivity	Recommendation	Respect for unique cultural issues	CAN	No reference	_

†There was no reference mentioned for this particular statement in the guideline, but because this statement is based on information about risk factors (high prevalences), it is probably based on the evidence about a higher prevalence in certain ethnic groups.

approaching ethnic differences. The USA and Canada, for example, have a long history of being multicultural societies with relatively large groups of native inhabitants and other subgroups. In the UK and the Netherlands, however, ethnic minorities are a more recent phenomenon resulting from labour and colonial migrants. These differences in historical background have led to political and cultural differences in facing questions concerning minority groups. Whereas the USA places both cultural and political emphasis on differences in ethnic identities, other countries do this to a lesser extent, resulting in other normative values. All these aspects could impact on the process of guideline development—for example, on the composition of the panel developing the guidelines which, in turn, could influence the process of decision making in the selection of relevant evidence and in the content of the guidelines.6 76-80 Although guidelines are considered to be products of evidence-based medicine and therefore primarily based on available scientific evidence, they always contain (either explicit or implicit) normative values of (individual) panel members.

Another factor to consider is the possibility that, because mainly local/national evidence was used to develop the ethnic specific recommendations, panel members in one country may consider that data are only applicable to ethnic groups in the country where the research was conducted. But do Afro-Americans in the USA differ from black subjects in the Netherlands and the UK; and do South Asians living in the USA differ from those in the UK, Canada or the Netherlands? As far as the medical differences discussed in this paper are concerned, the answer is probably not, because it is often reported that the higher prevalence and severity of diabetes

and hypertension in certain ethnic groups and the differences in response to drugs result, at least in part, from genetic differences and the migration process. $^{82.83}$

The above considerations raise interesting questions as to whether cultural differences between countries can explain different normative values between groups of guideline developers resulting in more or less ethnic specific recommendations in the guidelines, and whether health information about certain minority ethnic groups is applicable to similar groups in other countries. Since disease or health specific data on white subjects are accepted worldwide, it is legitimate to question why this does not apply to scientific data on differences between other ethnic groups. Future research should try to find the answers to these questions.

The development of guidelines is a complicated process in which many heterogeneous considerations are weighed against each other. Guidelines must be feasible and as clear, understandable and unambiguous as possible, given current healthcare practices. There will always be some reluctance about changes in current practice, and in describing exceptions and, for example, ethnic differences. Nevertheless, ethnic differences are present in all western societies and this issue can expect a higher priority in future research and health care. However, at present, the proportion of ethnic minorities in deprived neighbourhoods in the UK and the Netherlands is very large and, for the care in those underprivileged areas, ethnic specific recommendations in guidelines can already help practitioners in their daily practice and therefore should be implemented as soon as possible. If clinical recommendations do not accept the existence of clinically relevant ethnic differences in, for example, prevalence/complications and

Category	Type of statement	Statement about ethnic differences	Country	Evidence	Strengtl
Epidemiology	Empirical	Higher prevalence, more severe and higher risk for complications	USA	Klag (1997) ⁴¹	Ilb
	·			Burt (1995) ⁴²	III
				Fang (1996) ⁴³	III
				Singh (1996)44	III
				Havas (1996) ⁴⁵	IV*
				Hall (1997)46	IV*
			UK	Balarajan (1991) ⁵⁶	III
				McKeigue (1991) ⁵⁷	III
				Cappuccio (1997) ⁸	III
				Williams (1995) ⁵⁸	IV
Treatment	Empirical	Difference in response to pharmacological treatment	USA	Townsend (1990) ⁴⁷	lb
		, ,		SOLVD (1991)48	lb
				Materson (1993)49	lb
				Chen (1993)50	lla
				Chen (1995) ⁵¹	lla
			UK	Materson (1993)49	lb
	Empirical	Hypertension is sensitive to dietary salt restriction in black subjects		Weinberger (1996) ⁵²	IV*
		.,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	UK	No reference	_
	Empirical	Lifestyle modifications are particularly important	USA	No reference	_
	Recommendation	Black subjects require multi-drug therapy because of more severe	USA	Burt (1995)42†	III
		hypertension		Hall (1997)46†	IV*
	Recommendation	Achieve goal blood pressure of below 140/90 mm Hg	USA	Burt (1995)42†	Ш
		σ, σ		Hall (1997)46†	IV*
	Recommendation	Emphasis on glucose tolerance, lipids and increased coronary risk	UK	McKeigue (1991) ⁵⁷	III
		, 9 , , , , ,		Williams (1995) ⁵⁸	IV
	Recommendation	Good blood pressure control important in South Asians with diabetes	UK	No reference	-
	Recommendation	Aspirin and/or statin treatment may be indicated for South Asians at high risk of CHD	UK	No reference	-
	Recommendation	The start of drug therapy should be influenced by black race	CAN	No reference	-
Patient education	Empirical	Requirement of more focused education	USA	Enas (1996) ⁵³	III
	•			Howard (1996) ⁵⁴	III
				Winkleby (1996) ⁵⁵	III
				Havas (1996)45	IV*
	Recommendation	Advice to reduce fat and refined sugar intake and to increase exercise	UK	No reference	-

†There was no reterence mentioned for this particular statement in the guideline, but because this statement is based on information about risk factors (high prevalences), it is probably based on the evidence about a higher prevalence in certain ethnic groups.

response to pharmacological treatment, suboptimal or even harmful practices may occur. 84 This also applies to the need for ethnic specific education and counselling and sensitivity towards differences in cultural values and norms, particularly when a positive clinical effect has been proved. By disregard-

ing scientific evidence, the guideline may provide inaccurate information and thereby compromise the quality of care⁸⁴; and by disregarding scientific evidence, the higher morbidity and mortality and the higher risk of complications with hypertension and diabetes will continue or even get worse because,

Category	Type of statement	Statement about ethnic differences	Country	Evidence	Strength
Epidemiology	Empirical	Hospitalisation and death rates highest among black subjects	USA	CDC (1996) ⁵⁹	III
Diagnostics	Empirical	Lung function varies across ethnic groups	USA	Woolcock (1972)60	III
				Hsu (1979) ⁶¹	III
				Wall (1982) ⁶²	III
				Coultas (1988) ⁶³	III
				Crapo (1988) ⁶⁴	III
				Marcus (1988) ⁶⁵	III
				Coultas (1994) ⁶⁶	IV*
			NL	Quanjer (1983) ⁷⁴	IV*
				Quanjer (1993) ⁷⁵	IV*
Patient education	Empirical	Failure of attending education programs is associated with minority ethnic group	UK	Fitzgerald (1994) ⁷³	IV
	Recommendation	Asthma education in native language and sensitive to patient's culture	USA	Manson (1988) ⁶⁷	III
				Pachter (1993) ⁶⁸	III
				Pachter (1995) ⁶⁹	III
				Risser (1995) ⁷⁰	III
				Kleinman (1978) ⁷¹	IV
				Woloshin (1995) ⁷²	IV
Medical record	Recommendation	Sociocultural beliefs should be an item in medical history	USA	No reference	_

Key messages

- Guidelines from different countries differ in the attention given to ethnic differences between patients.
- Guidelines developed in the USA give the most attention to ethnic differences between patients compared with the UK, Canada and the Netherlands; Dutch guidelines give the least.
- Cultural differences between countries lead to differences in the content of guidelines.
- Although clinical practice guidelines are seen as products of evidence-based medicine, normative values also influence the content of guidelines.
- Disregarding scientific evidence about ethnic differences in guidelines could compromise the quality of care for ethnic minorities and could lead to unnecessary health problems in this group.

in the Netherlands, for example, members of the ethnic minority groups are relatively young and will therefore be faced with more morbidity in the future.

CONCLUSIONS

Differences in the attention given to ethnic differences between patients in clinical practice guidelines exist between countries. Whatever the explanations may be for these differences, guideline developers should be aware of the potential problems for patients from ethnic minority groups. Ethnic differences should play an important part in both screening the available evidence and in the development of the guideline—for example, the composition of the expert panel. With the increasing movement of people between countries, this aspect will become even more important in the future.

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