

Original Article

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Patient-physician agreement among vulnerable ethnic minority patients in Denmark

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ABSTRACT

INTRODUCTION Medical doctors in Denmark are clinically challenged by ethnic minority patients, resulting in delayed or incorrect treatments. Apart from language barriers, little is known about the nature of the challenges presented by ethnic minority patients. The present study investigated the level of agreement between the patients' main problems, doctors' referral notes and patient-reported problems documented at a hospital-based migrant health outpatient clinic.

METHODS A retrospective cross-sectional study was conducted on 150 patients referred to the Migrant Health Clinic (MHC), Odense University Hospital, Denmark. The study was based on a full "Problem list" that was co-produced with the patient. Cohen's kappa (κ) and Chamberlain's proportionate positive agreement (p_{ppa}) were calculated for the medical and socioeconomic problems described in the referrals and MHC notes, respectively.

RESULTS Significant agreement between patient and referring doctor was found for only two health complaints: musculoskeletal pain ($\kappa = 0.43$ and $p_{ppa} = 0.69$) and Type 2 diabetes mellitus ($\kappa = 0.71$ and $p_{ppa} = 0.59$).

CONCLUSIONS Doctors and patients rarely agree on the patients' health problems. Patient engagement such as co-production of care may potentially produce the time and resources needed to help doctors identify the patients' priorities and describe them in referrals.

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TRIAL REGISTRATION not relevant.

Medical doctors in Denmark struggle to provide adequate treatment for vulnerable ethnic minorities [1]. Many diagnoses and essential problems are overlooked even after repeated healthcare contacts, potentially causing delayed or incorrect treatments and reducing trust in the healthcare system [1, 2].

Language barriers is one of the main reasons for this [1]. Another is the complex nature of patients' problems including issues of health literacy, low socioeconomic status, multimorbidity and the prevalence of post-traumatic stress disorder (PTSD), etc. [1, 3]. Health is affected by social determinants such as short or no education, a low income and early loss of physical function [4, 5]. Furthermore, PTSD may impair the patient's cognitive function and alter the way they perceive and describe their symptoms, which may in turn mislead doctors when facing clinical decisions [3]. An impaired cognitive function may result in problems maintaining a steady income or keeping track of official appointments, i.e. with a healthcare contact [2, 3].

Identifying these problems early on and co-producing healthcare with the patient may possibly help doctors find a solution with which the patient may comply [6, 7]. Thus, studies have indicated that doctors who create solutions together with their patients based on the patients' needs and resources achieve more functional solutions. In contrast, doctors who provide solutions based on the needs and resources of the organisation tend to create dysfunctional solutions in which the patient is neglected [8, 9].

Currently, vulnerable ethnic minority patients are often hard to involve, and time pressure and language barriers steal time from patient engagement [7, 10]. A form of patient engagement coined "co-production of care" has shown that this problem may be remedied if both the system and the professionals are adequately prepared [7].

Aiming to assess a possible target point, this study investigated one of the key elements in coproduction of care: the physician's awareness of the patient's priorities.

The purpose of this study was to assess the level of agreement between vulnerable ethnic minority patients and their doctors regarding the perception of the patients' major health complaints.

METHODS

This was a retrospective cross-sectional study based on the records of 150 patients referred to the Migrant Health Clinic in Odense, Denmark. Patients were referred to the clinic between 7 June 2016 and 31 December 2018, either by their general practitioner or by a hospital department in the Region of Southern Denmark.

Data were collected between 1 March and 1 October 2019.

Setting

The Migrant Health Clinic is a public hospital-based out-patient clinic receiving vulnerable immigrant and refugee patients with complex health problems who are referred by general practitioners and hospital departments. The aim is to help the patients on multiple levels, and the clinic employs both doctors, nurses and social workers. One of the essential clinical tools is a "Problem list", an exhaustive list of patient-reported problems on which the patient is prompted to state all their problems regardless of their nature: medical, socioeconomic, psychological or other [11].

Only referral notes and notes from the two initial standard consultations were analysed in this study.

Participants

Only patients with at least the two standard consultations (including a "Problem list") were eligible for this study. Patients were chosen randomly from a chronological list of Danish Civil Registration (CPR) numbers using a random number generator. The list only contained the CPR numbers and a unique patient identifier coined the study subject ID.

Outcomes

The primary outcome was the level of agreement between the referral and the "Problem list", which is a list of problems coproduced with the patient when he or she first visits the Migrant Health Clinic [11].

The secondary outcome was the level of agreement between the referral and the full Migrant Health Clinic notes, including the "Problem list" and everything discovered during the two primary consultations at the clinic.

The tertiary outcome was to establish the number of patients with an overlap between one or more problems in the referral and the "Problem list" as well as the referral and the entire Migrant Health Clinic (MHC) note data

material.

Data sources and methods

Data were extracted from referral notes and from Migrant Health Clinic records produced during the two initial consultations. The Migrant Clinic records were divided into the “Problem list” and any remaining text, where the patient answers specific questions from the staff, the latter simply being categorized as “Observed problems”. Each specific problem could appear only once per patient to avoid overrepresentation.

The “Problem list” is an established tool in the clinic and was deemed the best estimate of the patient’s experienced problems [12].

Coding

From the referral notes and clinic records, three main descriptive areas were defined under which patient information was allocated: medical problems, socioeconomic problems and socio-demographic background factors.

Every new problem encountered in the referral or clinic notes was transferred to a Microsoft Access (2016, version 16) table and assigned a unique number as a code identifier.

Medical problems included diagnoses and physical and mental health complaints as well as compliance-, pharmacology- and treatment-related problems. Socio-economic problems included all current socio-economic and emotional issues. Finally, demographic factors consisted of descriptions of the patient and his or her environment that were not presented directly as a problem but as factors describing the patient’s situation.

The codes were based on previous studies at the clinic and adjusted during the course of the study (before the data were analysed statistically) [13].

Only the corresponding author conducted the data collection. The supervisor made random quality assurance checks.

Statistics

A minimum sample size of 88 patients was calculated using a 20% error margin and a 50% difference between the overall probability of agreement and the probability of agreement expected by chance alone, as suggested by Gwet [14].

To ensure a higher statistical power, a sample size of 150 patients was chosen before any statistical calculations were conducted as this was deemed possible within the time limit.

The chosen statistical software was RStudio Team (2018. RStudio: Integrated Development for R. RStudio, PBC, Boston, MA. V. 1.1.463), STATA (StataCorp. 2019. Stata Statistical Software: Release 16. College Station, TX: StataCorp LLC) and Microsoft Excel (2010).

To describe the level of agreement between patient-perceived problems and the referring doctor’s perception, Cohen’s kappa coefficient (κ) and Chamberlain’s proportionate positive agreement (p_{ppa}) were calculated [15, 16]:

First, the number (%) of patient referral pairs with at least one matching problem in the referral and MHC notes was calculated (see **Table 1**). Next, it was determined how frequently each problem was reported in the MHC notes only, in the referral only and lastly in both the referral and clinic notes (see **Table 1**). The number was calculated for the “Problem list” and the total MHC notes, respectively.

No p-value was calculated since the null hypothesis is generally not applicable to kappa [17]. Instead,

Chamberlain's p_{ppa} was calculated since κ is problematic when the prevalence of an overlapping problem is low compared with the total number of times it is mentioned [15]. The p_{ppa} was read as a regular proportion [15].

TABLE 1 Overlapping problems with a top five by prevalence (N = 150).

Overlap	Patients, n (%)	Top five			
		subjects	n	κ^a (interpretation)	p_{ppa}^b
<i>Referral > < "Problem list"</i>					
Medical	140 (93.33)	Musculoskeletal pain	84	0.43 (weak)	0.69
		Back problems	28	0.26 (minimal)	0.35
		Headache	24	0.42 (weak)	0.41
		Anxiety symptoms	15	0.49 (weak)	0.41
		Type 2 diabetes mellitus	13	0.71 (moderate)	0.59
Socioeconomic	30 (20.00)	Trauma	7	0.18 (none)	0.18
		Family's problems interconnected	3	0.25 (minimal)	0.18
		Assaults, accidents etc. in Denmark	3	0.40 (weak)	0.27
		Fear of disease	2	0.28 (minimal)	0.18
		Feeling pressured by municipality	2	0.08 (none)	0.08
<i>Demographics</i>					
Referral > < MHC notes	78 (52.00)	Refugee	20	0.11 (none)	0.24
		Attended language school WFS	10	0.06 (none)	0.11
		On social allowance	8	0.01 (none)	0.06
		Worked in home country	8	0.11 (none)	0.11
		Previously more than one inconsequential investigation	7	0.04 (none)	0.13
<i>Referral > < all MHC data, both "Problem list" and observed</i>					
Medical	146 (97.33)	Musculoskeletal pain	87	0.27 (minimal)	0.66
		Back problems	29	0.17 (none)	0.33
		Headache	27	0.14 (none)	0.28
		PTSD	20	0.37 (minimal)	0.36
		Anxiety symptoms	19	0.41 (weak)	0.37
Socioeconomic	65 (43.33)	Trauma	14	0.02 (none)	0.15
		Family's problems interconnected	7	0.29 (minimal)	0.23
		Loss of family member due to war/conflict in home country	5	0.25 (minimal)	0.18
		Conflict within family/with family members	5	0.47 (weak)	0.33
		Isolation tendency	4	0.04 (none)	0.08

MHC = Migrant Health Clinic; PTSD = post-traumatic stress disorder WFS = without further specification.

a) Cohen's kappa coefficient.

b) Chamberlain's proportion of positive agreement.

Although a κ -value of 0.80 is often recommended as the minimum accepted value of agreement, this depends on the type of measurement [16]. In this study, a κ -value of 0.6 or above (corresponding to moderate, strong, or almost perfect overlap) or a p_{ppa} of 0.6 or higher was considered sufficient agreement because of the expected complexity in defining the patients' problems.

Ethics

Only patients who consented to participate in the research and had this stated explicitly in the patient files were eligible for the study.

Permission to handle personal data was granted by the Danish Data Protection Agency R.no. 2016-41-4693 and by The Region of Southern Denmark R.no. 19/7712.

Trial registration: not relevant.

RESULTS

Most patients were female, from Syria and had lived in Denmark for about 14 years (see Table 2). Only two

patients did not require a translator. Often, both the patient and his or her partner were on social allowance (82% and 40%, respectively). Only 2% were currently working. Less than 50% had completed elementary school training and about 33% had worked in their home country and/or Denmark.

TABLE 2 Sociodemographic data based on clinic notes (N = 150).

	n (%)	Mean (95% CI)	SE	SD
Gender: female	99 (66.00)			
<i>Country of origin</i>				
Syria	47 (31.33)			
Afghanistan	16 (10.67)			
Iran	14 (9.33)			
Lebanon	14 (9.33)			
Somalia	12 (8.00)			
Turkey	10 (6.67)			
Iraq	8 (5.33)			
Other	29 (19.33)			
Age		46.98 (45.21-48.75)	0.90	10.96
Time lived in Denmark by referral time, yrs		13.97 (12.03-15.94)	0.99	12.08
Waiting time between referral and 1st MHC-visit, mos.		4.88 (4.47-5.29)	0.21	2.56
Waiting time between 1st and 2nd consultation, mos.		2.95 (2.66-3.25)	0.15	1.83
Patients with completed MHC period	75 (50.00)			
Time to completed MHC period, yrs		1.40 (1.24-1.56)	0.08	0.68
<i>Source of income</i>				
On social allowance	123 (82.00)			
On paid employment	3 (2.00)			
Partner/spouse on social allowance	61 (40.67)			
Partner/spouse on paid employment	20 (13.33)			
<i>Educational level</i>				
Never attended school	24 (16.00)			
Unfinished elementary school	45 (30.00)			
Finished at least elementary school ^a	63 (42.00)			
Finished at least high school level	22 (14.67)			
Attended university	16 (10.67)			
Education in home country unspecified	19 (12.67)			
<i>Language education</i>				
Attended language school in Denmark ^b	91 (60.67)			
<i>Previous working experience</i>				
Worked in home country	38 (25.33)			
Previously worked in Denmark	44 (29.33)			

CI = confidence interval; MHC = Migrant Health Clinic; SE = standard error; SD = standard deviation.

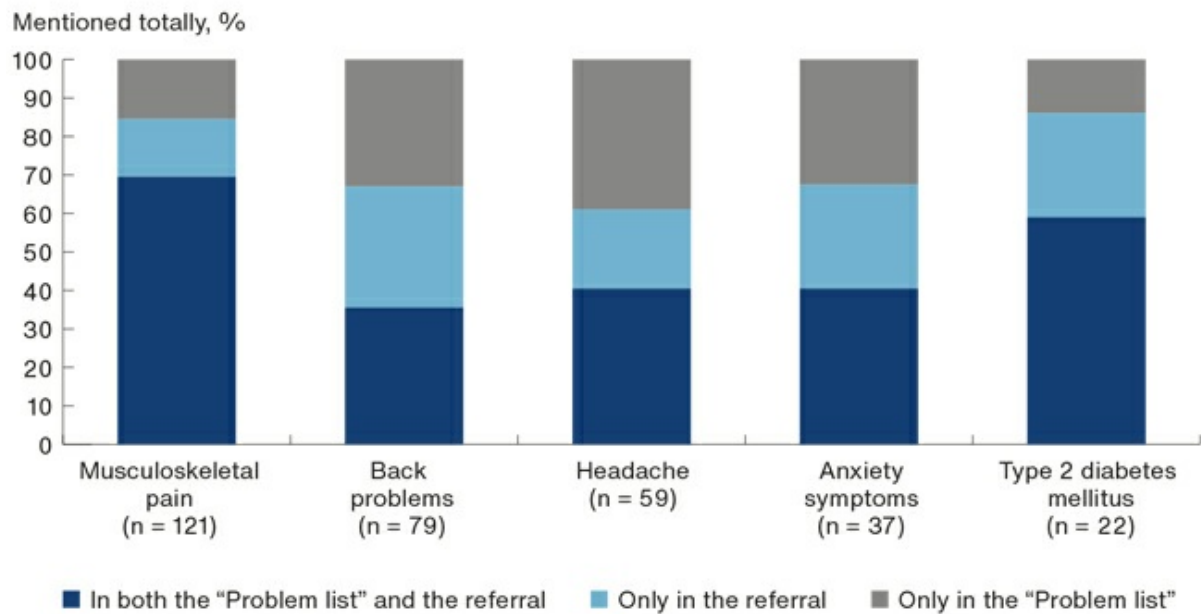
a) Defined as attending elementary school for ≥ 9 yrs.

b) Attended, not necessarily finished.

Only two codes were above the 0.6 cut-off in the primary outcome: musculoskeletal pain and Type 2 diabetes mellitus, and only musculoskeletal reached the 0.6 cut-off for pain in the secondary outcome (see Table 1).

In terms of the tertiary outcome, most patients had an overlap of one or more medical issues when comparing the referral to the “Problem list”, as well as the referral and the entire MHC data relating to the patient (93.33% and 97.33% respectively – see Table 1). When the patients had a wide range of problems, at least one patient-referral match for each patient may be expected. However, most problems were primarily mentioned in either the referral or the migrant notes and were rarely noted in both places for any single patient (see Figure 1).

FIGURE 1 Agreement between the patients and referring doctors on important medical problems: referral versus the "Problem list".



n = total number of times mentioned.

In contrast, only 20% of the patients had an overlap of one or more socioeconomic issues when comparing the referral and the "Problem list". This figure only rose to 43.33% when including all MHC data. A greater prevalence of socioeconomic issues such as trauma and financial difficulties was found in the clinic notes than in the referrals (see **Table 3**).

TABLE 3 Top five most prevalent problems (N = 150).

	Patients, n (%)	Top five subject	n (%)
<i>Medical</i>			
Referral	150 (100)	Musculoskeletal pain	102 (68.00)
		Back problems	53 (35.33)
		Headache	36 (24.00)
		PTSD	35 (23.33)
		Compliance issues in general	35 (23.33)
"Problem list"	150 (100)	Musculoskeletal pain	103 (68.67)
		Sleep disturbances in general	71 (47.33)
		Back problems	54 (36.00)
		Sleep disturbances due to racing thoughts and nightmares	50 (33.33)
		Headache	47 (31.33)
Observed ^a	148 (98.67)	Sleep disturbances in general	43 (28.67)
		Headache	42 (28.00)
		Low vitamin D level	38 (25.33)
		Shortness of breath	35 (23.33)
		Sleep disturbances due to racing thoughts and/or nightmares	33 (22.00)
MHC, total	150 (100)	Musculoskeletal pain	116 (77.33)
		Sleep disturbances in general	114 (76.00)
		Headache	89 (59.33)
		Sleep disturbances due to racing thoughts and/or nightmares	83 (55.33)
		Memory disturbances	71 (47.33)
<i>Socioeconomic</i>			
Referral	102 (68.00)	Trauma	24 (16.00)
		Family's problems interconnected	13 (8.67)
		Isolation tendency	10 (6.67)
		One or more family members diseased WFS	8 (5.33)
		Feeling pressured by municipality	8 (5.33)
"Problem list"	101 (67.33)	Trauma	22 (14.67)
		Feeling pressured by municipality	19 (12.67)
		Isolation tendency	18 (12.00)
		Financial difficulties	14 (9.33)
		Worries about relatives in home country	11 (7.33)
Observed ^a	144 (96.00)	Financial difficulties	78 (52.00)
		Trauma	60 (40.00)
		Problems with living situation	31 (20.67)
		One or more family members diseased WFS	30 (20.00)
		Child/children in trouble	30 (20.00)
MHC, total	148 (98.67)	Financial difficulties	92 (61.33)
		Trauma	82 (54.67)
		Isolation tendency	44 (29.33)
		Problems with living situation	36 (24.00)
		One or more family members diseased WFS	36 (24.00)
<i>Demographic factors^b</i>			
Referral	117 (78.00)	Previously more than one inconsequential investigation	41 (27.33)
		Refugee	35 (23.33)
		Previous psychiatric treatment: privately or at hospital	15 (10.00)
		Previously attended the department for trauma- and torture survivors	13 (8.67)
		Attended language school WFS	12 (8.00)
MHC, total	150 (100)	On social allowance	123 (82.00)
		Attended language school WFS	91 (60.67)
		Has contact with municipality	83 (55.33)
		Cannot read official letters in Danish without aid from relatives	82 (54.67)
		Temporary residence permit	70 (46.67)

MHC = Migrant Health Clinic; PTSD = post-traumatic stress disorder WFS = without further specification.

a) Only items not already on the "Problem list" were coded in "Observed", so the real number is likely higher.

b) Even if demographic factors appeared on the "Problem list", they did not count as problems and where typed separately. Therefore, all demographics in clinic notes are added to the "Total" category here.

DISCUSSION

For the primary and secondary outcomes, almost no agreement was found between the referring doctors and the patients regarding the patients' main problems. A considerable degree of overlap was found in the tertiary outcomes regarding the medical but not the socioeconomic issues.

Choosing only one reviewer ensured consistency and easily comparable results and allowed us to avoid interrater variability. Determining the problems based on short texts only is largely subjective and might be done differently in a similar study. The use of interpreters and the fact that the patients' problems were

documented by a staff member are limitations that may potentially mean that important points were omitted or misunderstood. However, the “Problem list” was co-produced and reviewed in cooperation with the patient several times by both a physician and a nurse, making it a unique strength of this study.

The frequencies of some problems were very low, especially in the primary outcomes and socioeconomic problems in general. This was partly due to the narrow problem definitions chosen in order to avoid a falsely high degree of agreement. This makes meaningful interpretation of the results in those categories harder. Larger studies or broader categories may provide a greater validity.

Disagreement between referrals and patient-reported problems is not limited to this patient group, but establishing a universal solution covering all patients was beyond the scope of this study [18].

This study does not suggest that the patient’s viewpoint is the right one – merely that it is not in line with the referring doctor’s viewpoint. The clinic will most likely uncover more problems than described in the referral, which is why the comparison of the referral and the entire MHC notes were only the secondary outcome. However, the referral and the “Problem list” should both be a condensed version of essential problems regarding the patient. The difference between the two indicates that doctors and patients focus on different issues. Co-production of care has shown promising results in terms of aligning the two, but will most likely require rethinking parts of the healthcare system [7]. Perceiving that this is an easy task that will likely yield results rapidly may not be realistic. Nevertheless, the challenges described within the patient group are already an issue and will presumably remain so if no measures are implemented. Testing and validating even small interventions might prove to save time and avoid some futile treatments and workups. Implementing changes in general practice rather than hospitals may be the easiest way to start, as GPs will likely have highest number of patient encounters. Possible interventions aiming to achieve a higher agreement include awarding the general practitioners with a higher fee for more in-depth consultations with complex patients. This will compensate the general practitioners for their effort and, hopefully, help make the patient-perspective clearer to the referring doctors.

Easy access to qualified interpreters is a simple way of increasing the level of patient-physician understanding. Lastly, screening for known problems within the patient group, especially non-medical issues, may be an applicable alternative to the systematic questioning used at the Migrant Health Clinic, as well as converting the “Problem list” into a tool tailored for the needs of general practice, to name but a few suggestions [19]. Further studies are warranted to develop and validate interventions within this patient group.

If co-production of care is not currently possible in general practice, new criteria for referrals may be needed to better equip the receiving departments. Presently, the referral must be a short overview of the patient’s situation phrased by the doctor [20]. Perhaps the referral could include a part representing the patient’s perspective to ensure that their priorities are clearer to the general practitioner and presented more adequately to the receiving department.

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