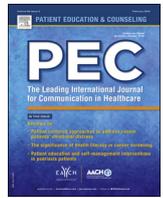




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Principles of effective communication with patients who have intellectual disability among primary care physicians

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ABSTRACT

Objective: Examine physicians' implementation of effective communication principles with patients with intellectual disabilities (ID) and its predictors.

Methods: Focus groups helped construct a quantitative questionnaire. The questionnaire (completed by 440 physicians) examined utilization of effective communication principles, attitudes toward individuals with ID, subjective knowledge and number of patients with ID.

Results: Subjective knowledge of ID and more patients with ID increased utilization of effective communication principles. Provision of knowledge that allows patients to make their own medical decisions was predicted by more patients with ID, lower attitudes that treatment of this population group is not desirable, less negative affect and greater perception that treatment of this group is part of the physician's role. Effective preparation of patients with ID for treatment was predicted by higher perception of treatment of this group as part of the physician's role, lower perception of this field as undesirable and higher perception of these individuals as unable to make their own choice. Simplification of information was predicted by a greater perception of treatment of this group as part of the physician's role and more negative affect.

Conclusion: Greater familiarity may enhance care for these patients.

Practice implications: Increase exposure to patients with ID within training.

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1. Introduction

Intellectual disability (ID) is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18 [1]. Since the 1990s, in line with the social model of disability, individualization, participation, normalization and inclusion have been the main principles of care for people with intellectual disability (ID) [2]. In line with this, article 25 of the United Nations' Convention on the Rights of Persons with Disabilities (CRPD) states that: "Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. Parties shall provide persons with disabilities with the same range, quality and

standard of free or affordable health care and programs as provided to other persons" [3]. Although people with ID often have more health problems than the general population, [4,5] these individuals, and their families, face many obstacles in seeking basic health care. Few providers receive specific training for treating this population and the health service systems in many countries offers few incentives to ensure appropriate health care for these patients. Consequently, studies have shown that individuals with ID frequently receive poorer health treatment [6]. In line with this, patients with ID have complained about the quality of communication with their physician, feeling that they are frequently misunderstood [19,28]. In addition, it has been shown that frequently the ability of an individual with ID to make a healthcare decision is not taken into concern while parents and professionals make these decisions on their behalf [16]. The 2001 report of the US National Institute of Health identified six main goals for improving health care of this population, which included improving the knowledge, understanding and training of health care providers [7].

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Many barriers to the provision of primary care for people with ID relate to problems in exchanging health information between the patient and the primary physician. Part of the problem is related to ineffective communication between the patient with ID and the treating physician [8]. This is also true in the general population where negative assessments of physician communication skills are associated with higher general dissatisfaction with the physician [9]. However, the difficulties related to poor communication are more likely when the patient has ID.

Very few attempts have been made to map communication principles with patients with ID. Using relatively small samples and mainly qualitative research techniques, these studies have led to the development of preliminary guidelines for effective communication principles with patients with ID. These include: (1) focusing on the abilities of the individual and not the disability, (2) developing a trusting relationship, (3) keeping eye-contact and speaking directly with the patient using speech that is adequate to the patients' age, (4) asking for the patient's permission before involving their support figure, (5) as much as possible, gathering the medical history from the patient him/herself, (6) making sure the patient knows that at any stage he can ask his support figure to leave the room, (7) using a variety of communication techniques in order to fit the patient's understanding, (8) making sure the physician has sufficient time for the practice visit, (9) explaining and demonstrating procedures before starting any physical examination [10–12,19]. Though these guidelines are very important, little research has examined their actual implementation and utilization by the primary care physician. Further, previous research has not examined how attitudes held by physicians may impact on the implementation of these communication principles. The aim of this study was to examine primary care physicians' implementation of effective communication principles with patients who have ID and its predictors. The correlates examined in this study are mapped in Fig. 1.

2. Methods

2.1. Study design

This was a mixed methods study based on qualitative and quantitative research methods. First, qualitative focus groups (N=4) and interviews (N=13) were held with four groups of informants: individuals with ID, parents of individuals with ID, direct care takers and physicians in order to elicit effective communication principles. Adults with ID and direct care takers were a convenience sample recruited from residential settings for persons with ID. Parents of adults with ID were a convenience sample recruited by Akim (the National Association for the Habilitation of Children and Adults with Intellectual Disabilities). Physicians were recruited via purposive sampling, reaching out for physicians whom the authors (and colleagues) know to be familiar with the ID field. Interviews were conducted by two of the authors who are highly trained in conducting these types of studies as well as a research assistant who was trained by the researchers. Results from this phase were used for the construction of a quantitative questionnaire.

This questionnaire was then distributed to physicians either as an internet link via their email or via a telephone interview. First, an online questionnaire was constructed using Google docs questionnaires. The link to the questionnaire was distributed via e-mail by the Maccabi Research and Evaluation Unit to all physicians in their registry (n = 1258). The e-mail sent described the importance of the study and its aims. Physicians were provided with two follow-up e-mail reminders. These questionnaires could be accessed and completed on any computer. One hundred and six physicians answered the internet version (8% response rate), but 17 were removed due to missing values. Second, phone interviews were conducted by experienced interviewers working at the Cohen Institute for Public Opinion Research. The researchers provided the

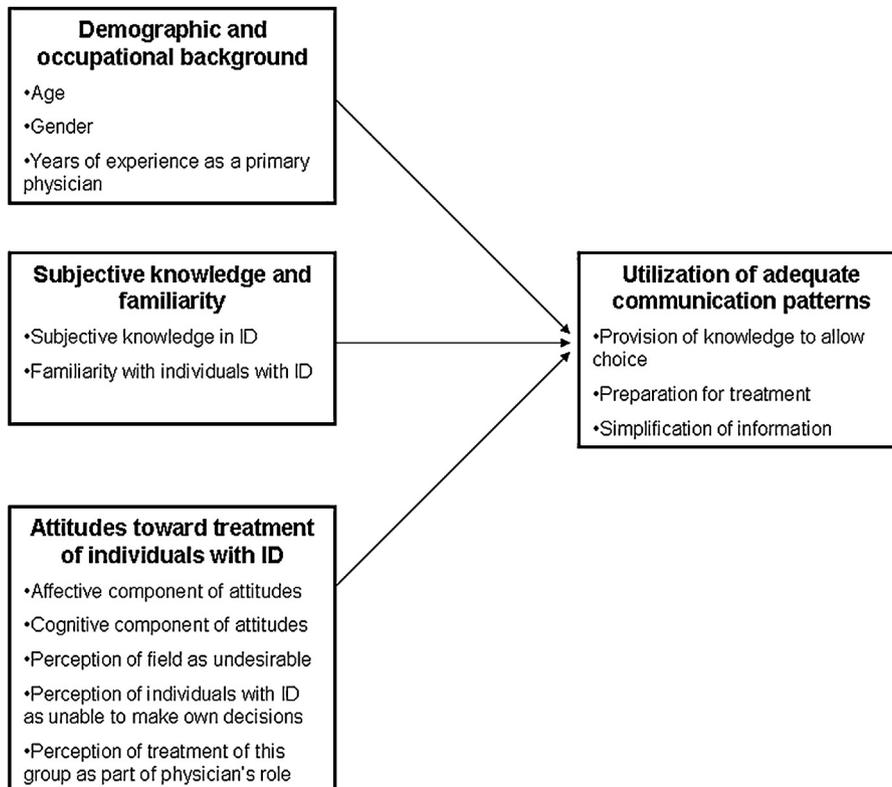


Fig. 1. Study model.

Cohen Institute with a listing of all Maccabi physicians and their clinic phone numbers. The Institute sampled 757 telephone numbers of those physicians who were initially invited to answer the online survey. These phone interviews were set-up as reminders following the online survey in the case that response rate to the online version may be low. Interviewers called the physicians' secretaries to set up an appropriate time for a phone interview. Of the telephone numbers 113 were removed as they were double names (as some physicians work in more than one Maccabi clinic), 42 were incorrect numbers, 5 physicians reported that they had already completed the online version, 15 were on vacation and in 2 interviews there were language difficulties. Thus, the number of relevant physicians for the interviews was 580. The telephone version of the questionnaire was completed by 351 physicians, i.e. a 60.5% response rate.

The study protocol was approved by the Ethics Committee of the Paul Baerwald School of Social Work and Social Welfare within the Hebrew University of Jerusalem as well as by the Helsinki Committee of the Maccabi Health Maintenance Organization. All participants were asked to provide their consent before their participation in both the qualitative and quantitative parts of the study. All data in this study were stored within the password protected personal computer of the main PI.

2.2. Instruments

Focus groups and qualitative interviews were based on an interview guide that focused on the experiences of meetings between patients with ID and physicians among the four informant groups. In particular, participants were asked to comment on their positive and negative experiences and on the specific components which helped develop effective communication patterns within these encounters. Sample questions from parents interviews (which were adapted to the other informant groups) included: "Tell me about a meeting your son/daughter had with a physician. How would you describe the communication during this meeting?"; "What do you think your son/daughter appreciated most in this meeting?"; "What bothered your son/daughter during this meeting?"; "How do you think communication between your son/daughter and his physician can be improved?"; "Describe what communication patterns with the physician are preferable in your perspective and for your son/daughter." Length of face to face interviews lasted between 10 and 40 min while focus groups lasted 90 min.

The quantitative questionnaire was developed based on results of the above described focus groups and interviews, existing literature and instruments [12–14], an unpublished instrument (Scior, personal communication) and the UK's General Medical Council's website (<http://www.gmc-uk.org/learningdisabilities/>). This questionnaire was composed of four sections that examined:

Utilization of Effective Communication Principles: Participants rated 18 items for the degree to which they believe that primary care physicians complete each when treating an individual with ID as compared to individuals without ID. In order to deal with possible social desirability bias in answering a direct questionnaire, items in this section were worded indirectly by asking the physician to rate what other physicians would do. The underlying notion in indirect questioning is that participants actually project their own opinions under the facade for another person [15]. For example, "To what degree do primary care physicians employ plain language when treating individuals with ID as compared to individuals without ID". Items were rated on a 5 point Likert scale ranging from 1 = much less than with a patient without ID to 5 = much more than with a patient without ID. Exploratory factor analyses with varimax rotation showed that this scale was composed of three factors: provision of information in order to

allow choice (for example, "Provide a patient with ID with all the information that will allow him to take the decision that is most suitable for him", $\alpha = .69$), preparation of individuals with ID for treatment (for example, "Allocate time for preparation or guidance regarding a medical or invasive procedure", $\alpha = .63$), and simplification of information (for example, "Simplify the information they provide", $\alpha = .54$). Four items were dropped following factor analyses.

Attitudes toward Treatment of Individuals with ID: Participants rated their degree of agreement to each of 21 items on a 5 point Likert scale ranging from 1 = highly disagree to 5 = highly agree. For example, "Most patients with ID are unable to provide informed consent for medical treatment". Exploratory factor analyses with varimax rotation revealed that this scale was composed of four factors, one negative affect factor (for example, "Feel stressed when treating patients with ID", $\alpha = .78$) and three cognitive factors, namely: perception of the field of treatment of individuals with ID as undesirable (for example, "Patients with ID need a separate and specialized clinic", $\alpha = .70$), perception of individuals with ID as unable to make their own decisions (for example, "A patient with ID always needs the aid of the physician or a family member in order to decide regarding his condition", $\alpha = .64$), and perception of treatment of this population group as part of the physician's role (for example, "Physicians believe that treatment of patients with ID is part of their roles as physicians", $\alpha = .53$). Three items were dropped following factor analysis.

Demographic and Occupational Background of the Physician.

Knowledge and Familiarity of the ID Field: included one item measuring degree of subjective knowledge in the ID field (1 to 5 scale with 5 indicating greater knowledge) and familiarity was measured by number of patients with ID under the treatment of the physician in the past year (recoded as a dichotomous variable of 0 to 5 versus 6+).

2.3. Data analyses

Qualitative content analyses were employed in order to elicit examples of adequate communication principles between primary care physicians and patients with ID. Each communication principle was worded as a questionnaire item for the quantitative instrument. Face validity of the questionnaire items was examined by the research team and expert physicians in the field, leading to shortening the instrument and rephrasing necessary items. Further, face and content validity tests were performed within two pilot studies with 46 physicians. These physicians were asked to answer two open-ended questions asking "In your opinion, what are the three most important factors in communication with patients who have ID?" and "In your opinion, are there any other important factors in communicating with patients with ID which we have not listed?"

Quantitative data analyses were conducted using SPSS. First, descriptive analyses were conducted to show the means, range and standard deviation of the main study variables. Second, Pearson correlations were conducted between subjective knowledge of ID and each of the effective communication factors as well as each of the attitude toward treatment of patients with ID factors. Third, independent samples *t*-test were utilized to examine the differences between each of the effective communication factors as well as each of the attitude toward treatment of patients with ID factors between those physicians that have more versus those physicians that have fewer patients with ID. Fourth, Pearson correlations were conducted to examine the association between attitudes toward patients with ID and use of effective communication principles. Finally, hierarchical regressions were used to examine the prediction of each of the three factors of effective communication principles.

3. Results

3.2. Results of study

3.1. Description of study population

Participants in the qualitative phase were six adults with mild to moderate ID, nine parents of adults with ID, three direct care takers and seven primary care physicians who were experienced in the ID field. Participants in the quantitative phase were a representative sample of 440 primary care physicians who work within Maccabi Health Maintenance Organization in Israel (35% of all physicians within Maccabi HMO). Of these physicians, 255 (58.0%) were male, the average age was 52.3 (SD = 11.2). Fifteen participants were removed from data analyses due to a large amount of missing data, leaving 425 physicians within the data set.

Means and standard deviations of each of the three effective communication principle factors and all items that compose these factors are shown in Table 1. As seen, physicians less frequently offer patients with ID information which allows choice regarding their physical treatment. However the physicians frequently prepare patients with ID for treatment and most frequently provide these patients with information in plain language.

Means for each of the items on attitudes toward treating individuals with ID and the four overall factors are shown in Table 2. As seen, physicians hold relatively positive attitudes toward the treatment of this patient group. Specifically, the physicians strongly identify with statements that these patients

Table 1
 Factors related to utilization of effective communication principles (N=425).

Factor	Range	Mean	SD
Provision of information to allow choice	1.20–4.60	2.66	0.60
Provide a patient with ID with all the information that will allow him to take the decision that is most suitable for him		2.61	1.03
Provide all the needed information to a patient with ID		2.63	0.89
Allow a patient with ID to take the decision himself		2.05	0.63
Speak to the patient with ID directly and not through his support worker or family member		2.52	0.87
Ask a patient with ID to repeat the information provided in order to make sure he/she understood		3.49	1.00
Preparation of patients for treatment	1.60–5.00	3.46	0.56
Allocate time for preparation or guidance regarding a medical or invasive procedure		3.60	0.61
Conduct a full physical examination		3.00	0.68
Attempt to create a calm and quiet environment in the clinic without disturbances		3.56	0.78
Explain to a patient with ID the medical procedures that the physician will perform		3.42	1.26
Be flexible with clinic rules, e.g. shorten waiting time or treat a patient with ID without his clinic card		3.74	0.79
Simplification of information	1.67–5.00	4.14	0.57
Simplify the information that they provide		4.30	0.73
Make use of simple language		4.27	0.81
Provide a patient with ID only with the minimal information that they need		3.52	0.87
Make use of gestures and body language		3.85	0.83

Table 2
 Factors related to physician's attitudes toward patients with ID (N=425).

Factor	Range	Mean	SD
Negative affect^a	1.00–5.00	3.45	0.57
Feel uncomfortable in a medical meeting with a patient with ID		3.42	0.78
Feel difficulty in conducting a medical examination for a patient with ID		3.46	0.72
Feel stress when treating patients with ID		3.39	0.69
Feel frustrated when treating patients with ID		3.48	0.78
Perception of field of treatment of ID as undesirable^b	1.00–4.33	2.03	0.74
Physicians prefer not to treat patients with ID		1.84	1.11
Many physicians will agree to treat patients with ID only if they do not cause disturbance in the clinic		2.02	1.24
Even if a patient with ID has good communication skills, physicians still think it's more efficient to speak with the care-taker first		2.37	1.25
Patients with ID need a specialized separate clinic		1.63	1.12
Treating patients with ID is one of the least desirable medical fields		2.91	1.35
It is preferable to treat other patients rather than patients with ID		1.42	0.93
Perception of individuals with ID as unable to make own decisions^c	1.00–5.00	2.75	0.94
A patient with ID always needs the aid of the physician or a family member in order to decide regarding his/her condition		2.93	1.28
Most persons with ID are unable to provide informed consent for medical treatment		2.32	1.16
It is important to let a patient with ID make his/her own decision about what is right (reverse coded)		3.01	1.19
Perception of treatment of this group as part of physician's role	2.80–5.00	4.33	0.48
Physicians believe that treatment of patients with ID is part of their roles as physicians		4.34	0.79
There's a need for greater sensitivity in order to understand the needs of a patient with ID		4.25	0.83
Most persons believe that preventive medicine and making periodical examinations are just as important for patients with ID as for patients without ID		4.27	0.92
People with ID have an equal right to receive good medical services as anyone else		4.79	0.48
It is important to provide more time for the examination and treatment of patients with ID as compared to patients without ID		4.02	0.98

^a Higher score indicates stronger negative feelings.
^b Higher score indicates greater perceptions of an undesirable field.
^c Higher score indicates perceptions of lower ability to make their own decisions.

Table 3

Association between subjective knowledge and utilization of effective communication principles and attitudes toward treatment of individuals with ID.

	Subjective knowledge of ID (r value)
Utilization of effective communication principles	
Provision of information to allow choice	0.13**
Preparation of patients for treatment	0.16***
Simplification of information	0.09
Attitudes toward treatment of individuals with ID	
Negative affect ^a	−0.16***
Perception of field of treatment of ID as undesirable ^b	−0.21**
Perception of individuals with ID as unable to make own decisions ^c	0.02
Perception of treatment of this group as part of physician's role	0.20***

^a Higher score indicates stronger feelings of burden, difficulty, discomfort and frustration.

^b Higher score indicates greater perceptions of an undesirable field.

^c Higher score indicates perceptions of lower ability to make their own decisions.

** $p < .01$.

*** $p < .001$.

should be an integral part of their workload. In line with this, their support for the perception of this field of treatment as undesirable was below the midpoint of the scale. However, physicians also reported feeling some discomfort in treating these individuals. Finally, their perception of patients with ID as lacking the ability to

make their own healthcare decisions was rated just above the midpoint of the scale.

Greater subjective knowledge of ID was found to be positively associated with provision of information to allow patients to make choice and with preparation of patients with ID for treatment (Table 3). In addition, greater subjective knowledge of ID was negatively associated with negative affect and with the perception that the field of treatment of ID is undesirable, while it was positively associated with the perception that treatment of this patient group was part of the physician's role. Thus, physicians who felt they had greater knowledge in the ID field reported greater inclination to utilize effective communication principles in the treatment of these patients and less likely to hold negative attitudes toward their treatment.

Physicians that had more patients with ID reported that they provided more information to patients with ID in order to allow them to make a choice and provided more preparation for treatment to these patients as compared to physicians that had fewer patients with ID (Table 4). In addition, physicians who had treated fewer patients with ID reported a greater negative affect as compared to physicians who treated more patients with ID. Thus, physicians who had treated more patients with ID were more likely to utilize effective communication principles and to report on lower negative affect.

When correlating between attitudes toward patients with ID and use of effective communication principles (Table 5), findings show that negative affect or the perception of this field as an undesirable medical field, was associated with less provision of information that would allow patients to make a choice and less preparation of the patient for treatment. In addition, negative affect was positively associated with simplification of information. Further, the perception of treatment of this patient group as part of their role was positively correlated with all three effective communication principles. Finally, the perception of individuals with ID as unable to make their own decisions was positively associated with clearly explaining and preparing these patients for healthcare treatment.

Table 6 presents the results of three hierarchical regressions for the prediction of each of the three factors in utilization of effective communication principles. In the first stage of each regression, background and occupational variables were entered. As a high correlation was found between age and years of experience as a physician ($r = 0.90, p < .001$), only age and gender were entered at this stage. In the second stage of each regression subjective knowledge and number of patients that the physician treated within the previous year were entered. In the third stage of each regression, the four factors of attitudes toward the treatment of individuals with ID were entered. Training in the ID field was not used as only 22 physicians reported on receiving any training.

Regression 1 predicted 12.7% of the variance in provision of knowledge to allow choice for patients with ID ($F_{(8,399)} = 7.26, p < .001$). Utilization of these effective communication patterns was predicted by: having more patients with ID, older physicians, lower scoring of the attitude that treatment of this population group is undesirable, fewer negative feelings related to this population and greater perception that treatment of this group is part of the physician's role. Regression 2 predicted 16.1% of the variance in preparation of a patient with ID for treatment ($F_{(8,399)} = 9.60, p < .001$). This factor was predicted by higher perception of treatment of this group as part of the physician's role, lower perception of this field of treatment as undesirable, higher perception of individuals with ID as unable to make their own choice and older physicians. Regression 3 predicted 10.3% of the variance in simplification of information ($F_{(8,399)} = 5.71, p < .001$). This factor was predicted by holding a greater perception of

Table 4

Differences in utilization of effective communication principles and attitudes toward treatment of individuals with ID according to number of patients with ID.

	Number of patients with ID Mean (SD)	T-test
Utilization of effective communication principles		
Provision of information to allow choice		4.57***
0–5 patients	2.51 (0.55)	
6+ patients	2.77 (0.61)	
Preparation of patients for treatment		2.59***
0–5 patients	3.37 (0.53)	
6+ patients	3.51 (0.57)	
Simplification of information		1.27
0–5 patients	4.10 (0.58)	
6+ patients	4.17 (0.57)	
Attitudes toward treatment of individuals with ID		
Negative affect ^a		3.43*
0–5 patients	3.51 (0.51)	
6+ patients	3.41 (0.41)	
Perception of field of treatment of ID as undesirable ^b		1.49
0–5 patients	2.09 (0.71)	
6+ patients	1.98 (0.75)	
Perception of individuals with ID as unable to make own decisions ^c		0.59
0–5 patients	2.78 (0.92)	
6+ patients	2.73 (0.95)	
Perception of treatment of this group as part of physician's role		2.10*
0–5 patients	4.28 (0.49)	
6+ patients	4.37 (0.47)	

^a Higher score indicates stronger feelings of burden, difficulty, discomfort and frustration.

^b Higher score indicates greater perceptions of an undesirable field.

^c Higher score indicates perceptions of lower ability to make their own decisions.

* $p < .05$.

*** $p < .001$.

Table 5
Correlations between attitudes toward patients with ID and use of effective communication principles.

Attitudes toward individuals with ID	Utilization of effective communication principles		
	Provision of information to allow choice	Preparation of patients for treatment	Simplification of information
Negative affect	−0.21 ^{***}	−0.12 [*]	0.12 [*]
Perception of field of treatment of ID as undesirable	−0.17 ^{***}	−0.21 ^{***}	0.03
Perception of individuals with ID as unable to make own decisions	−0.06	0.12 [*]	0.03
Perception of treatment of this group as part of physician's role	0.16 ^{***}	0.32 ^{***}	0.23 ^{***}

^{*} $p < .05$.
^{***} $p < .001$.

Table 6
Hierarchical regression for the prediction of utilization of effective communication principles.

Variable	Regression 1: Provision of information to allow choice (n = 408)			Regression 2: Preparation of patients for treatment (n = 408)			Regression 3: Simplification of information (n = 408)		
	B	B SE	β	B	B SE	β	B	B SE	β
Step 1									
Age	0.01	0	.17^{**}	0.01	0	.18^{***}	−.00	0	−.09
Gender ^a	0.01	0.06	0.01	−.05	0.06	−.04	−.13	0.06	−.12 [*]
Step 2									
Age	0.01	0	.16^{**}	0.01	0	.17^{**}	−.01	0	−.10
Gender ^a	−.02	0.06	−.02	−.06	0.06	−.05	−.15	0.06	−.12 [*]
Subjective knowledge	0.02	0.04	0.03	0.06	0.04	0.08	0.07	0.04	0.08
Number of patients with ID ^b	0.24	0.06	.20^{***}	0.09	0.06	0.08	0.06	0.06	0.06
Step 3									
Age	0.01	0	.14^{**}	0.01	0	.11[*]	−.01	0	−.11
Gender ^a	0.02	0.06	0.02	−.02	0.06	−.02	−.13	0.06	−.11 [*]
Subjective knowledge	−.02	0.04	−.02	0	0.04	0	0.04	0.04	0.06
Number of patients with ID ^b	0.21	0.06	.18^{***}	0.08	0.05	0.07	0.06	0.06	0.05
Affective component of attitudes ^c	−.12	0.05	−.12 [*]	−.02	0.05	−.02	0.12	0.05	.12[*]
Perception of field of treatment of ID as undesirable ^d	−.08	0.04	−.11 [*]	−.14	0.04	−.19 ^{***}	0.01	0.04	0.01
Perception of individuals with ID as unable to make own decisions ^e	−.06	0.03	−.09	0.07	0.03	.12^{**}	0.05	0.03	0.08
Perception of treatment of this group as part of physician's role	0.14	0.05	.11[*]	0.32	0.06	.27^{***}	0.26	0.06	.22^{***}

Bold indicates significant variables.

^a 0 = female, 1 = male.

^b 0 = 0–5 patients in past year, 1 = 6+ patients in past year.

^c Higher score indicates stronger feelings of burden, difficulty, discomfort and frustration.

^d Higher score indicates greater perceptions of an undesirable field.

^e Higher score indicates perceptions of lower ability to make their own decisions.

In regression 1: $R^2 = 0.03$ ($p < .01$) for 1st step, $\Delta R^2 = 0.04$ ($p < .001$) for 2nd step, $\Delta R^2 = 0.06$ ($p < .001$) for 3rd step.

In regression 2: $R^2 = 0.03$ ($p < .01$) for 1st step, $\Delta R^2 = 0.02$ ($p < .05$) for 2nd step, $\Delta R^2 = 0.12$ ($p < .001$) for 3rd step.

In regression 3: $R^2 = 0.03$ ($p < .01$) for 1st step, $\Delta R^2 = 0.01$ ($p < .01$) for 2nd step, $\Delta R^2 = 0.06$ ($p < .001$) for 3rd step.

^{*} $p < .05$.

^{**} $p < .01$.

^{***} $p < .001$.

treatment of this group as part of the physician's role, holding more negative feelings and by female physicians.

4. Discussion and conclusion

4.1. Discussion

Findings from this study provide additional support and expand upon the effective communication principles that have been mapped in previous studies [10–12,19]. Specifically, findings provide support for the importance of simplifying information to the patient by speaking directly to the patient and adapting speech to the patients' understanding and using a variety of techniques such as gestures and body language. Second, results point to the importance of preparing the patient adequately for treatment by proving them with a calm clinic environment, explaining procedures and providing ample time in order to guide the patients before physical examination. In addition, results point to the importance of listening to the patient and providing them with

information and knowledge so that they are able to make their own healthcare decisions.

Physicians who participated in this study moderately supported the perception that individuals with ID are not capable of making decisions regarding their health and healthcare. This is problematic as these physicians may fail to provide opportunities for patients with ID to make their own decisions and voice their opinions. Autonomy has become an important issue for these people and can be defined as self-determination and independence: 'A behavior is considered to be autonomous if the person acts (a) according to own preferences, interests, and/or abilities and (b) independently, free from undue external influence or interference' [2]. Not providing these patients with adequate autonomy is a cause for concern as it has been previously shown that the ability of patients with ID to decide is usually not assessed or addressed by most physicians [16]. This is at variance with research that shows that these patients are indeed capable of learning skills that allow independent decision making [17]. In accordance with suggestions of the CRPD, it may be that

the best way forward requires a supported decision-making model [18].

This study shows that the attitudes of physicians, specifically, if they felt that treatment of individuals with ID should be part of their role, was one of the more important predictors of effective communication with this group of patients. Similarly, physicians that felt that this is an undesirable field of medicine, offered less information allowing less autonomy and were less active in explaining and preparing the patient for treatment. These findings are similar to those of previous research [19]. Interestingly physicians who felt that patients with ID were unable or find it difficult to make their own healthcare decision, invested more in preparing the patient for treatment and explaining what will happen. Physicians who found interaction with patients with ID stressful, offered less information and explanations although they made an effort to simplify information. This finding has been reported previously and may possibly be related to fear of the physician from uncertainty regarding aggressive behavior of patients with ID in consultations [20].

Findings from this study are worrying as previous studies have shown that healthcare decisions taken by another person on behalf of the individual with ID may expose this individual to an unbalanced and discriminatory decision which may not be in concordance with the patients' values, wishes or needs [15,21–23]. Difficulties in allowing these individuals equal opportunities in their healthcare decisions may be related to two main reasons: First, the health service system, which results in limited time granted for each patient may negatively influence the use of effective communication principles [24]. Second, physicians may be wary about allowing too much choice due to a fear that these patients may not make a decision in their best interest, thus compromising their treatment [25].

Another important finding of this study was that degree of familiarity, measured by number of patients with ID which the physician treated, was associated with provision of information to allow choice. This finding is in line with previous research which has suggested that patients expressed greater satisfaction when they were treated consistently within the same service and by the same physician, i.e. a physician that was familiar with them [26]. Further, familiarity encourages an understanding of the patients' right to receive information and state their opinion. Another explanation is that by familiarity with these patients the physician can learn about individual differences between individuals with ID, and the great variability of their abilities and strengths. In addition, and importantly, the physician can get acquainted with the individuals' communication patterns including non-verbal language, eye contact and body language. Learning these will aid in improving the comfort level of both the physician and the patient.

The study results have to be interpreted with caution in view of its limitations: In this study we asked physicians to report on how they believed their colleagues would behave toward patients in order to reduced social desirability bias. However, we can only assume that their report reflected their own views. Second, we were unable to assess the effect of specific training that physicians may have had in the field of ID given so few physicians reported on any training and those that did report of training did not detail its scope. Thirdly, the study utilized a survey design which investigated self-reported and not actual behavior of the physician, thus we cannot reach conclusions about causality. In addition, the survey was conducted in two ways, via an online and phone interview. Four, physicians were recruited from only one HMO which covers 25% of the population. Nevertheless, we do not see a reason that physicians working in this HMO would differ from those working in others. Further, many physicians in the HMO also work in other clinical settings. The strength of this study is the high response rate of primary care physicians to the questionnaire.

4.2. Conclusion

The study results suggest that the primary medical care for patients with ID could be improved by increased physician familiarity with patients with ID. Such exposure during their training has shown a significant improvement in medical students' communication skills, comfort and type of clinical approach which will raise the quality of care provided by them in the future [27].

4.3. Practice implications

Results of this study point to the need to develop supported decision making models for use by physicians working with patients with ID. Training of physicians should encompass the use of simplification of information, accessibility of language used by the physician, use of gestures and body language, use of visual aids and other assistive technologies which may aid in enhancing the individuals' understanding of the information provided and their choices.

Conflict of interest

The authors have no potential conflicts of interest.

Informed consent

I confirm all personal identifiers have been removed so that the persons described are not identifiable and cannot be identified through the details of the story.

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