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GPs' opinions of health assessment instruments for people with intellectual disabilities:

a qualitative study

Abstract

Background

GPs provide health care to people with intellectual disabilities (ID). People with ID find it difficult to express themselves concerning health-related matters. Applying health assessments is an effective method to reveal health needs, and can play a role in prevention and health promotion.

Aim

The aim of this qualitative study was to explore GPs' considerations about applying a health assessment for people with ID.

Design and setting

This focus group study was conducted among a selection of Dutch GPs.

Method

An interview guide was developed. All discussions were audiotaped and transcribed. Analysis was performed using the framework analysis approach. Two researchers independently applied open coding and identified a thematic framework. This framework and the summaries of views per theme were discussed in the research team.

Results

After four focus groups, with 23 GPs, saturation was reached. Three main themes evolved: health assessments in relation to GPs' responsibility; the usefulness and necessity of health assessments; and barriers to using health assessments on people with ID. A health assessment instrument for people with ID can help GPs to focus on certain issues that are not so common in the general population. GPs are motivated to use such a tool if it is scientifically tested, and results in significant health gains. However, GPs identify barriers at the level of GP, patient, and organisation.

Conclusion

Most GPs in the focus groups consider providing medical care to people with ID their responsibility and indicate that a health assessment instrument could be a valuable tool. In order to deliver good care, they need education and support. Many barriers need to be overcome before a health assessment instrument can be implemented.

Keywords

focus groups; general practice; intellectual disability; primary health care; qualitative research.

INTRODUCTION

People with intellectual disabilities (ID) have a significantly reduced ability to understand new or complex information, and to learn and apply new skills (impaired intelligence). Therefore, the ability to cope independently is reduced, resulting in impaired social functioning.¹ People with ID often have difficulties in expressing themselves concerning health issues, leading to health disparities.^{2,3} Their difficulties in recognising illnesses and diseases often lead to a significant patient and/or doctor delay.⁴ Premature deaths for people with ID are mostly due to problems in receiving appropriate care, due to delays or problems with investigating, diagnosing, and treating illnesses.^{5,6}

Applying health assessments by means of questionnaires, focusing on highly prevalent diseases for people with ID, have proven to be an effective method to detect health needs, and can play an important role in health monitoring and health promotion.⁷⁻¹¹ Research has shown increased disease detection, as well as an increase in prevention and health promotion activities.⁷⁻¹⁰ Most patients with ID valued the use of health assessment instruments positively.¹²⁻¹⁶ In residential care in the Netherlands, medical care for people with ID is often delivered by

a specialist ID physician. ID physicians are medical physicians who have undertaken a 3-year vocational training course. (In 2000 the Dutch minister of health recognised the medical care for people with ID as a new medical specialisation. The 3-year postgraduate training for physicians takes place at the Erasmus University in Rotterdam, as a part of the institute for training of GPs. It consists of a combination of working and learning in the field of care for people with ID. Part of the training is an orientation in closely related fields of medicine, like neurology, genetics, and psychiatry). Nowadays, many Dutch residential care facilities have an outpatient clinic for people with ID to which GPs can refer patients. Outside the residential care facilities, GPs are involved in delivering health care to people with ID. In Australia and the UK, GPs are encouraged by their governments to carry out health assessments on people with ID.^{17,18}

GPs experience difficulties in the care of these patients. Lack of knowledge and time constraints are among the most important difficulties for GPs.¹⁹ A health assessment instrument can help the GP to detect medical problems of people with ID in a structured and comprehensive way. It also helps GPs to overcome communication barriers.²⁰

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Submitted: 8 May 2016; **Editor's response:** 31 August 2016; **final acceptance:** 5 October 2016.

© British Journal of General Practice

This is the full length article (published online 20 Dec 2016) of an abridged version published in print. Cite this version as: **Br J Gen Pract** 2016; DOI: 10.3399/bjgp16X688585

How this fits in

Due to Dutch government regulations more people with intellectual disabilities (ID) will stay and live in the community; GPs, instead of ID physicians, will become responsible for their medical care. People with ID experience health disparities, and health assessment instruments can reveal their health needs. The results of this study indicate that GPs are motivated to use such a tool if it is scientifically tested and results in significant health gains. With regard to delivering good care, they also need education and support. GPs identify barriers at the level of the GP, the patient, and the organisation. These barriers need to be overcome in order to implement a health assessment instrument.

Healthcare professionals, including GPs, agreed on the use of a comprehensive health assessment programme.^{8,21} In another study, GPs preferred to be involved in the assessment directly, and not after referral by another physician.²²

However, health assessment instruments for people with ID are not yet commonly applied in the Netherlands. Therefore, the aim of this qualitative study was to explore Dutch GPs' opinions about applying a health assessment instrument for people with ID in daily practice.

METHOD

Study design and participants

Focus group interviews with Dutch GPs were conducted and reported according to the consolidated criteria for reporting qualitative research (COREQ).²³ This qualitative method is appropriate to explore and clarify what GPs think about using health assessments for people with ID. As health assessments for people with ID are not yet used in the Netherlands, GPs can only talk about their expectations, as opposed to their own experience. In these cases, focus groups are helpful to formulate an opinion on unfamiliar topics through discussion.²⁴ GPs were recruited through e-mail and telephone contact. A purposive sampling strategy was applied to ensure heterogeneity in the characteristics of the participating GPs, such as age, sex, type of general practice, and experience with the care of people with ID. The aim was to include participants with different levels of medical experience and sympathy for working with people with ID. The target number of GPs in each focus group was five to eight participants. The invitation letter provided information about the research question, the goal of the

project, the moderator (GP), the researcher (ID physician), and practical information.

All GPs gave informed consent. Anonymity and confidentiality were ensured, and participants gave permission for an audiorecording of the discussion. Participants were offered a €20 gift voucher, study points, and reimbursement of travel expenses. Approval of an ethics committee according to Dutch legislation was not required.

Focus group interviews and data collection

The moderator of the focus groups was a female GP and senior researcher with extensive experience in qualitative research. The observer of the focus groups was a female ID physician and PhD student. The observer made field notes. All focus group discussions took place in the conference room of a general practice. The authors developed an interview guide based on the literature and discussions within the research group. After each focus group discussion, the interview guide was slightly adjusted to explore the entire field of the research question (progressive focusing).²⁵ The discussions lasted 75–90 minutes and all focus group discussions were audiorecorded and transcribed verbatim by a medical student. The observer checked the transcripts and corrected these when necessary.

Analysis

Data analysis was performed using the framework analysis approach. This type of analysis is suitable to meet specific information needs and provide outcomes or recommendations.^{26,27} The five key stages of the analysis process (familiarisation, identifying a thematic framework, indexing, charting, mapping and interpretation) were included.²⁸ All transcripts were uploaded in ATLAS.ti (version 7.5) to support qualitative data analysis. The transcripts were read frequently to gain familiarity with the data and open (unrestricted) coding was applied. Data collection proceeded until saturation was reached, meaning that no new major themes emerged from the data. The initial coding was discussed, and a code book was developed with definitions of the codes. During this process, themes were identified and discussed. The themes that reflected the research question formed the thematic framework. During the index stage, the thematic framework was systemically applied to all data (transcripts). All quotes belonging to a certain theme were charted. Through abstraction and synthesis, summaries of views were formulated per theme. These summaries were discussed in order to define the final concepts.

RESULTS

GP participants

Thirty-six GPs were invited to participate; of these, 13 GPs indicated that they were too busy to participate or the date was not suitable for them. In total, 23 GPs participated in four focus groups between December 2014 and February 2015 (Table 1).

Three main themes were identified from the data: GPs' responsibilities with regard to health assessments for people with ID in primary care; the usefulness and necessity of a health assessment; and barriers for GPs when using health assessments for people with ID in daily primary care.

GPs' responsibilities with regard to health assessments for people with ID

Most GPs consider medical care for people with ID their full responsibility, as people with ID live in the community. In order to deliver high-quality care for people with ID, GPs emphasised that specific tools, education, and support are needed:

'I think that all GPs could do with some extra tools, education, and support in order to provide this group with good care.' (GP B, female, 59 years)

GPs stated that they are familiar with delivering integrated care to specific groups of patients, such as older patients. Furthermore, they indicated that the practice nurse could play a role in

supporting them in this type of care:

'Wouldn't it be possible to deploy a practice nurse (PN), just like you do in elderly patients, in order to monitor these people in one way or another?' (GP K, female, 57 years)

Some GPs stated that they would like to see people with ID themselves as this would give them the opportunity to get to know the patient with ID better. A number of GPs suggested that medical care for people with ID is not a task for the GP, but for the ID physician.

They mentioned that GPs are not competent enough with regard to medical knowledge and experience to deliver high-quality medical care for this section of the population:

'This is a very specific field, of course. It's too absurd for words that GPs should simply do this "on the side". I think it's irresponsible, really.' (GP U, female, 47 years)

Other GPs stated that their ID physician colleagues could act as a facilitator in the care for people with ID living in the community. For example, the ID physician could help GPs to identify patients with ID who are in need of a health assessment.

However, when complexity increases, GPs prefer the opportunity to refer these patients to the ID physician:

Table 1. Characteristics of the 23 participating GPs

	<i>n</i>
Sex	
Male	11 (47.8%)
Female	12 (52.2%)
Mean age, years (range)	47.4 (29–67)
Mean experience as GP, years (range)	16.6 (0–38)
Location GP practice	
Rural area	6
Urbanised area	5
Urban area	8
Other	4
Experience with people with intellectual disabilities (ID)	
Yes	21
Little	2
No	0
Estimated number of patients with ID in GP practice (range)	
Mean	82 (10–350)

'I would be in favour of this ... to look more closely as a GP, if I'd have certain information about an elderly patient or if I'd suspect that someone has intellectual disabilities. A first and second level assessment I could do myself. But if an assessment would become more extensive and complex, I'd call in an ID physician, for instance, and wouldn't do it myself.' (GP F, female, 34 years)

Furthermore, they stressed that GPs already face lots of time constraints and that they are not able to spend much time on the care for people with ID.

Usefulness and necessity of health assessments

GPs indicated that, if people with ID experience difficulties in expressing themselves concerning health-related matters, health assessment instruments could help them to deliver proactive care:

'Generally speaking, I think that you [as a GP] often need to adopt a much more proactive approach, as you need to know what kind of problems you can expect [when dealing with patients with ID], and check actively whether these problems are indeed present. You need to assume there's every chance that people don't mention that problem themselves or ... if they do, they use other words.' (GP B, female, 59 years)

This proactive care could result in the detection of new diseases, and the prevention of serious complications. GPs noticed that this is especially important regarding people with ID, as the impact of medical complications on their lives is often significant:

'Yes, because they [patients with ID] have difficulties expressing their health problems in a clear way. The complications are not pleasant for anyone, of course, but things will become even worse for them. She was already deaf and now she has poor eyesight as well. Yes, I think that it's very important to screen people with ID.' (GP U, female, 47 years)

Furthermore, a health assessment instrument for people with ID might also help GPs to focus on certain specific issues that are more common in the ID population. According to GPs, a health assessment instrument can provide an overview of the multiple problems people with ID encounter. GPs are often not aware of the specific health problems of people with ID:

'I think it's a very good idea to be presented

with some sort of problem list or such a tool being made available. Then at least you'll have some sort of guideline, an overview of problems they might have.' (GP S, female, 36 years)

'I can think of a number of patients I've seen in practice of whom I know by now they have disabilities. They consult me on a regular basis, but it's hard to find out what their request for help is and what is the best way to help them. I would really like to give them such a list.' (GP F, female, 34 years)

'This group of people [people with ID] has a high rate of comorbidity. So they often have three or four problems instead of one. I think this could help me to be ... constantly aware of that.' (GP G, female, 64 years)

However, at the same time, GPs acknowledge that awareness among GPs is urgently needed as they do not always recognise patients with ID:

'Yes, and a question I find very interesting is one that has not yet been fully answered: how are you going to raise awareness among GPs? I think it's a very nice screening instrument and all, but before it can be used something else has to be done. Yes, that's what I think.' (GP M, female, 38 years)

'I think there's still a very large group [of people with ID] that has not yet been diagnosed and for that reason gets stuck.' (GP M, female, 38 years)

GPs indicated that a health assessment tool for people with ID could help them with caring for these people. However, such a tool should be scientifically tested and result in significant health gains:

'I'd be motivated to use such an instrument, if I'd know for certain it'd be of significant benefit.' (GP L, male, 67 years)

'I would also like to know what research has been done, what the results are, how much is actually being overlooked, and whether there is any evidence before introducing such a comprehensive tool as an integral part of the health care for people with intellectual disabilities.' (GP H, female, 63 years)

Barriers to using health assessment instruments in daily practice

GPs identified multiple barriers against the use of health assessment instruments in delivering health care to people with ID. These barriers are at the patient level, GP

Table 2. Barriers to using health assessment instruments

Patient level	GP level	Organisational level
<ul style="list-style-type: none"> • Group of patients with intellectual disabilities (ID) is diverse • Communication problems • Large system around patient • Little continuity of care • Care system not medically trained 	<ul style="list-style-type: none"> • Don't recognise patients with ID • Don't want to stigmatise • Feeling incompetent • Attitude/affinity • Don't want to somatise • Fear medicalisation • Aversion to checklists • Checklists hinder conversation 	<ul style="list-style-type: none"> • Extra time needed • Payment needed • Increased workload • More people needed • Patient with ID is not registered

level, or organisational level (Table 2). This study has separated the barriers, but in daily practice they are intertwined.

Barriers at patient level. GPs stated that communication with the patient, and the whole (care) system that surrounds the patient, is often quite complicated. According to GPs, this is due to a lack of continuity of care, and the fact that caregivers/daily-care professionals are often not medically trained. Urgent medical needs of people with ID can easily be missed or not recognised. They fear that this barrier will also interfere with using health assessments. If daily-care professionals do not recognise medical symptoms, they cannot support the patient or the GP during the health assessment:

'Yes, that makes it more difficult, I've noticed in practice. Communication-wise, it's very difficult to explain something to them and to deal with that.' (GP O, male, 37 years)

'That's my experience, too. People [care professionals] often have good intentions, which is fine of course. But they lack medical training and knowledge, and information may not be passed on correctly. So if you want to carry out such things [health assessments], you need someone who can be present, too, a practice nurse for instance.' (GP A, male, 62 years)

Barriers at GP level. GPs indicated that they do not always recognise patients with ID. They experience an enormous heterogeneity in this group of patients and they discuss the uniform approach to this heterogeneous group of patients. Furthermore, some GPs hesitate to label a patient with an ID diagnosis as they do not want to stigmatise them:

'But it's all relative, of course, as you're

talking about a very large group that is actually very diverse. I think that the majority of patients you see in practice are high-level clients. I experience a big difference between them and the group of obviously lower-level clients. So I find it very difficult to put them all in the same box.' (GP M, female, 38 years)

GPs brought up that they generally felt incompetent to deliver good quality of care for their patients with ID. GPs used the following terms for their own feelings: 'ignorant', 'action embarrassment (not knowing how to deal with the situation)', 'feeling powerless', 'incapable', and 'incompetent'. Some GPs showed affinity and a positive attitude with patients with ID, whereas others did not. GPs indicated that they do not like to somatise patients with ID. GPs fear that applying health assessment instruments may lead to over-medicalisation:

'Some people [GPs] don't like going to an institute at all, because they, well, they just don't know how to deal with them [people with ID]. I hear a lot of complaining, whereas I just think that people [GPs] often feel powerless and incompetent. So it's very difficult.' (GP M, female, 38 years)

'You are somatising them [people with ID] a bit, and ... it is often rather troublesome for them to go to a doctor ... so it'd better be useful.' (GP S, female, 36 years)

Some GPs pointed out that they have a strong aversion to checklists. In their opinion, checklists can hinder good conversation and communication with the patient:

'It seems very useful in some respects, but my reluctance to these types of lists is ...

that so many boxes need to be ticked that there's no time to ask them how they are ... that the entire communication process, well, you should watch that filling in these lists doesn't hinder the communication. I'm aware that's not the intention.' (GP B, female, 59 years)

Barriers at organisational level. GPs noted that they do not always label patients with ID with a specific ICPC (International Classification of Primary Care) code in the GPs' medical system. The reasons given for this were that some GPs did not know this code, whereas others did not want to stigmatise the patient. Therefore, it is not easy to select patients with ID from the practice list in order to invite them for a health assessment:

'Well, for a start, there is a group of people of whom we don't even know they have intellectual disabilities ... And if we do, we don't write it down. It's taboo to record such a thing.' (GP A, male, 62 years)

GPs indicated that using a health assessment on people with ID will take extra time and increase their workload, therefore, to implement such an assessment more staff would be needed. Furthermore, the additional effort of GPs should be financially rewarded:

'Because I'd like that, too, but without good financing and support it's not easily feasible.' (GP A, male, 62 years)

'If you'd ask what's been most successful, then it's the list the doctor doesn't need to fill in, you see ... Because the management of diabetes improved a great deal when the practice nurses got involved. We [GPs] aren't very good at this. Like I said before, we'll need more people, if they're going to implement these kinds of things.' (GP A, male, 62 years)

DISCUSSION

Summary

A health assessment instrument for people with ID in primary care is a tool to help the GP to focus on prevention of highly prevalent diseases in the ID population, on public health issues, and on health promotion. GPs' considerations about using health assessment instruments for patients with ID focus on three main themes: GPs' responsibility concerning health assessments for patients with ID; the usefulness and necessity of using health assessments; and the barriers GPs

expect to encounter. Most GPs consider providing medical care to patients with ID their responsibility; others emphasise cooperation with ID physicians and/or practice nurses; and some believe this specialised care belongs to trained ID physicians. GPs stress that specific tools, education, and support are needed in primary care. They are willing to use a health assessment instrument, if the tool is scientifically tested and its use leads to significant health gains. However, GPs also identify many barriers, such as the diversity of patients with ID, difficulties with recognition of patients with ID, problems with registration (with the consequence that it is impossible to select patients with ID as a group), communication difficulties with the patient and the care system, insufficient knowledge, resistance against checklists, fear of medicalisation, and lack of resources (time, staff, and money). In the light of these findings, it will not be straightforward to implement health assessment instruments in primary care. A remarkable finding is that GPs hesitate to record people with ID in their system, as they do not want to stigmatise them. However, a recent study showed that 100% of the patients with ID were happy with the health check; all were willing to come back next year.²⁹ Awareness among GPs needs to be stimulated in recognising people with ID. This recognition can lead to better person-centred medical care instead of stigmatisation.

Strengths and limitations

A rigorous qualitative method was applied in this study: data collection continued until saturation was reached, and open coding was applied independently. As far as the authors are aware, this is the first study using focus group discussions with progressive focusing, and in accordance with the COREQ guidelines on this subject in ID literature.

Although measures were taken to include a heterogeneous group of GPs, GPs without affinity to patients with ID may have been missed. GPs without affinity might have mentioned additional and/or alternative considerations and barriers. The representative quotations needed to be translated into English, which may have led to some loss of meaning.

Comparison with existing literature

GPs' feeling of responsibility for the medical care of people with ID was also found in other studies.^{30,31} The same is true for the fear of an increased workload, and reluctance to carry out health assessment programmes

for people with ID.^{30,31} In the current study, GPs indicated that the practice nurse and ID physician could play a role in supporting the GP in this type of care. This fits with other studies which show that GPs rely on key support workers to enable them to carry out this role.³¹ GPs prefer to be involved in the assessment directly, and not after referral by another physician.²² Communication difficulties, high staff turnover, and poor understanding of a patient's symptoms, mentioned in a study about general medical care to people with ID, resemble the outcomes in the authors' research.³² A health assessment implementation study noticed better health care, uncertain benefits, organisational barriers, and more engagement between the person with ID, their care provider, and the GP.²⁰ In contrast with other research, this study did not find that GPs view patient histories as unclear and that they fear a lack of compliance with the GPs' management plans.³²

The attitudes of GPs towards other instruments for screening in primary care, such as those for screening depression and cardiovascular risk, resemble the attitudes mentioned in this present study.^{33,34} The GPs in these other studies describe the loss of unique information by using an instrument, the uncertainty of how to integrate the instrument in the consultation, the poor fit between the application of a questionnaire with the role of a GP, and time constraints.^{33,34}

Implications for research and practice

The evidence of the impact of a health check on the wellbeing of people with ID is described in a review study.^{9,10} In the authors' systematic review (EJ Bakker-van Gijssel, unpublished data, 2016) 20 different health assessment instruments for people with ID were found. However, there were many deficits in the scientific development of all instruments. First, there is a need to develop and validate a health assessment instrument according to evidence-based principles and focus on the suitability of this instrument in primary care. The Dutch primary care system resembles the system in the UK. Every citizen has their own GP. However, at the moment primary care in the Netherlands is subject to major changes. In the slipstream of these changes, the authors hope that more attention will be paid to primary care for people with ID. Second, greater focus is required on a number of organisational barriers, such as the education of professionals in primary care and the implementation of the ICPC code for intellectual disabilities. The first step is the course developed by the Dutch College of General Practitioners, together with the Department of Primary and Community Care at Radboud University Medical Centre. Third, as fear of stigmatising patients with ID appeared to be one of the main barriers to good care, this needs to be highlighted when educating GPs, and the specific reasons for this fear explored.

Funding

This study was supported by the consortium 'Stronger on Your Own Feet', in which the Radboud University Medical Centre collaborates with the following care organisations for people with ID: Pluyn, Siza, Dichterbij, Oro, de Driestroom, 's Heerenloo, Philadelphia, de Twentse Zorgcentra, and Koraalgroep.

Ethical approval

Approval of an ethics committee according to Dutch legislation was not required.

Competing interests

The authors have declared no competing interests.

Acknowledgements

The authors thank Lex van Son, medical student at the Radboud University Medical Centre, for his contribution and assistance with the verbatim transcription.

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