Intellectual disability and mental health problems: a qualitative study of general practitioners' views

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Complete List of Authors:	Fredheim, Terje; Sykehuset Innlandet, Religionspsykologisk senter Haavet, Ole; University of Oslo, Department of General Practice Danbolt, Lars; Innlandet Hospital Trust, Psychology of religion Kjønsberg, Kari; Innlandet Hospital Trust, Psychology of religion Lien, Lars; University of Oslo, Division of Mental Health and Addiction
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Intellectual disability and mental health problems: a qualitative study of general practitioners' views

Terje Fredheim[1,4]*, Ole R Haavet[4] Lars J Danbolt[1,3], Kari Kjønsberg[1], Lars Lien[1,2],

[1]Centre for Psychology of Religion, Innlandet Hospital Trust (SIHF), Hamar, Norway

[2] Division of Mental Health and Addiction, Oslo University Hospital, and University of Oslo, Oslo, Norway

[3]Norwegian School of Theology, Oslo, Norway

[4]Department of General Practice, University of Oslo, Oslo, Norway

* Corresponding Author:

Terje Fredheim, Religionspsykologisk Senter, Postboks 68, N-2312 Ottestad

E-mail: terje.fredheim@sykehuset-innlandet.no

Phone: 0047 - 41219155

Article summary

Article focus

- The aim of this study was to investigate the general practitioners (GPs) experiences in handling people with intellectual disabilities and mental/behavioural problems (MBP) in order to identify factors related to high quality services, important areas for improvement and suggest fields for further exploration.

Key messages

- This study shows that GPs have different opinions on central subjects in providing high quality services to people with ID and MBP.
- Even GPs with an assumed high competence and engagement in this patient group, lack evidence based knowledge and base their actions on experience based practice.
- GPs are concerned about the competence in specialist departments when it comes to treatment of MBP in people with ID

Strenghts and limitations in this study

- Participants were of both genders, from several localities and had a broad range of patients with ID and MBP.
- As far as we know, this is the only study that has addressed GPs experiences with people with ID and MBP.
- Although data across participants were found sufficient, a small group of participants were interviewed.

Abstract

Objectives To investigate general practitioners' (GPs) experiences in handling people with intellectual disabilities (ID) and mental and behavioural problems (MBP).

Design Qualitative study using in-depth interviews.

Setting General practice in Hedmark County, Norway.

Participants 10 GPs were qualitatively interviewed about their professional experience regarding people with ID and MBP. Data were analysed by all authors using systematic text condensation.

Results The participants' knowledge was primarily experience based and collaboration with specialists seemed to be individual rather than systemic. The GPs provided different meanings for referral, treatment, collaboration, regular health checks and home visits.

Conclusions GPs are in a position to provide evidence-based and individual treatment for both psychological and somatic problems among people with ID. This potential is not yet fully exploited. The findings in this study provide useful information for further research in the field.

Introduction

People with intellectual disabilities (ID) are particularly vulnerable to health problems and experience difficulties in meeting their health care needs.[1-7] Two recent attempts provide a focus to this challenge: a consensus manifesto by the European Association of Intellectual Disability Medicine[8] and an independent inquiry on a request from the British Secretary of State for Health.[9] These reports share the goal of improving health care services for people with ID, but the extent to which their recommendations have been implemented remains dubious. A recent meta-analysis has shown that the prevalence of ID is approximately 1%.[10] Prevalence of mental health problems among people with ID vary in different studies from 14% to 60% and can be difficult to identify and diagnose.[11] There is considerable overlap between mental health problems and challenging behaviour[12,13]; these two complications are often inseparable, suggesting that there is little to gain from distinguishing between them when trying to identify implications for health workers.

To detect and treat people with ID and mental and behaviour problems (MBP) is a test of the competence of the general practitioner (GP). Doctors specialising in general practice acquire knowledge about the early and general presentation of diseases, and early treatment and follow-up of chronic disease. GPs play a central role because of their familiarity with other primary health care services, as gate-keepers to specialist health care and in evaluating treatment and cooperate with the patient, family and other service providers.[14-17]

Each Norwegian GP has 5 to 10 patients with ID on their list. Some of these patients will have MBP, which potentially influences their physical health, including poor diet; erratic compliance with medication; and behaviour that can affect physical health, creating the need for close care and structure in health services.[18]

The importance of closely monitored care and high-quality health services to meet the challenge of inequality in health services for people with ID have provided the focus for several papers.[1,4,6,7,19] There is however few studies that have looked at the way GPs are working with patients with ID and MBP. The aim of our research was to explore the experiences, competence, attitudes and role of GPs providing health services to people with ID, with a special focus on people with ID and MBP.

METHODS

A qualitative method

We opted for a qualitative approach, in order to obtain more detailed descriptions of the GPs' experiences serving people with ID and MBP. In-depth interviews are suitable in inquiring about the GP's experiences, facilitating a deeper understanding of their opinions and attitudes.[20,21] We preferred open interviews to focus on each participant's descriptions and experiences, and bringing narratives into the method, by giving participants the opportunity to provide meaning to their responses.

Participants

Data were drawn from a total of 10 interviews with 10 participating GPs aged 41 to 64 (table 1). Participants were chosen following recommendations from an acknowledged senior psychiatrist with more than 30 years of experience with ID patients in collaboration with GPs in Hedmark County. There are 173 GPs in Hedmark, and the senior psychiatrist considered 25 of them to have more than the usual level of experience with ID patients and a relatively large number of ID patients on their list. A letter was sent to 15 of these GPs, purposefully selected with regard to geographical location and gender. It was estimated that a sample size of 7 to 10 participants would be required to achieve sufficient data and identify key themes. Of these 15, 10 GPs were able to participate, 3 GPs refused to participate, and 2 GPs did not respond. Participation in this study was voluntary, and each participant signed an informed consent form, and was informed of their right to withdraw from the study at any time, without further explanation.

TABLE 1

Participant number	Age	Gender	Location	Total number of patients	Approximate number of ID patients	Reported number. of ID patients with psychiatric/ behavioural challenge
1	58	F	Rural	950	6	2
2	61	M	City	1200	3	2
3	60	M	Rural	800	14	4
4	64	M	City	2500	20	10
5	60	M	Rural	750	15	6
6	61	M	City	1000	5	?
7	60	M	City	1100	30	20
8	42	F	Rural	850	7	3
9	59	M	Rural	1000	12	6
10	41	F	Rural	1300	10	5

Participants' number, age, gender, location, total number of patients, approximately number of patients with ID, and reported number of ID-patients with mental or behavioural problems

Setting

All 10 interviews were conducted in the GPs' offices, and lasted 41–81 minutes, with a mean of 57 minutes. Interviews were conducted from October to November 2011 and were audio recorded. All but one interview was conducted by two of the authors (TF and KK) and consisted of open-ended questions based on an interview guide with two main questions:

1. What are your experiences with ID patients who have additional mental health problems and/or challenging behaviour?

2. What do you think is the GP's role for these patients?

The additional checklist was used to gather information that was otherwise missing or to provide greater depth or breadth to incomplete information. Typical follow-up questions addressed the number of patients in the GP's patient group, collaborative partners, if regular health checks were provided and attitude towards psychotropic treatment of challenging behaviour.

Analysis

The interviewers made field notes with the participants' frequently used words, phrases and other statements requiring follow-up. Pauses, engagement, laughter and gestures were also noted, and the field notes were used in addition to the total transcripts. Analysis of transcripts was conducted using systematic text condensation.[20,22,23] The first author read the transcripts several times to obtain a sense of the whole. The other authors independently read the transcripts and identified meaningful units, themes and subthemes, trying to capture the "essential expression". These findings were discussed among the authors.

RESULTS

During the interview, GPs described their experiences, consultations and collaboration with a variety of relatives and professionals. Case presentations included descriptions of ID patients with complex medical, psychiatric and behavioural challenges. As a model of analysis, the process of a consultation emerged from the material as the best description of the GPs' experiences with this group of patients (figure 1). This model illustrates a GP's pathway through a consultation with four main categories: basis for decisions, consultation, treatment and follow-up.

Figure 1 approximately here

Basis for decisions

The main category, *basis for decisions,* epitomizes the GP's knowledge and experience in the context of the patient group and describes their medical education, experiences, courses and relevant post-graduate education on this topic. The GPs described limited training in patients with ID from their medical school or post-graduate courses. None of them had knowledge of the Norwegian Medical Association's Internet-based course on the topic. There was no mention of articles, books or peer-reviewed journals on the topic:

> *I think… those medications that I am used to prescribing, and that I know are effective in any or another way, I will use them as a common guideline. (GP #1)*

> *I have common knowledge about patients and psychiatry. I have a large number of patients and I have years of experience. (GP #4)*

Knowledge of the patient and continuity in the relationship between patient and physician were seen as key issues in providing the best service. Furthermore these GPs saw the advantage of being a family doctor, improving the relationship to the patients allowing the GP to make a better job of evaluating the biological, psychological and social strengths of the patients. As one participant said:

> *The family will be a support system for the patient anyway, so l see this as a great advantage. (GP #6)*

A key finding in this category is that most of the treatment is founded on experience-based knowledge. The material was rich in descriptions of patient histories, organisational system changes and historical events in the ID health care service, together with private memories from childhood or random meetings with people with intellectual disability. Because experiences are individual, there were many different stories, opinions and points of view.

> *Already in primary school I went to a school where people with ID were integrated. Having contact with people with ID has never been strange or unfamiliar for me. (GP #8)*

Consultation

The second main category, *consultation*, covers type of consultation, communication and individual routines or rituals by either the GP or the patient. First there are descriptions of various types of consultations which can occur in either the office or the patient's home: acute consultation, planned evaluations of treatment and prescriptions, and health checks. The GPs varied in their opinions about the benefits and possibilities of seeing the patient at home, as quotes from these two doctors illustrate:

> *Home visits are soon to become a closed chapter in general practice, but with these patients I find it necessary to do home visits. Then I can see with my own eyes how things appear at home (GP #5).*

> *They need to be observed and… it is not always easy for a GP to be able to observe. A GP should stay in the office and be available for patients (GP #4).*

Furthermore the GPs have different opinions about the benefits and possibilities of regular health checks for this patient group. Lack of standard guidelines opens the door for individual solutions and a variety of explanations. One participant highlighted this patient group as bad requesters of health care, requiring closer follow-up:

> *We may not be optimally good at this, but we try to do it once a year, and that is about were it ends. Some have a health problem that leads to more frequent consultations; in those cases a yearly health control is less important. But in general these are patients who don't tend to promote themselves. (GP #9)*

Communication and observation is another cluster of experiences in this category. Some of these patients are obviously anxious about a consultation, and all GPs said that their focus was on the patient, communicating directly with the ID patients, even though they were accompanied by others. If something could not be done because of unwillingness or restlessness, they did not push the patient, but booked another appointment in the near future.

There were many descriptions of patients who went through special routines and rituals in their GP's office. It seemed to be important for the relationship between the GP and the patient that these routines be followed; the patient tended to be calmer allowing the doctor to undertake the necessary investigations. As one participant said:

> *He is sitting here, takes a glass of water, sits down again and drinks some water. Sometimes I am able to check his blood pressure and do blood tests. He was not able to do that with his previous GP (GP #1).*

Our participants argued that their patients' should be accompanied by someone who knows the patient, their medical history and the reason for the consultation. Yet patients with communication problems were sometimes accompanied to the doctor's office by health workers with limited knowledge of the patient. Because GPs must rely on information from accompanying persons, they would sometimes send the patient home with a new appointment. As one participant said:

> *It is essential that we have confidence in the information we are given. And that it is not exaggerated, hyped or trivialized, but is a sober description that it is possible for me as a GP to navigate towards (GP #7).*

Some participants were more likely to use systematic consultations and follow-up, especially if the patient had chronic somatic problems. Nevertheless, the somatic problem, rather than the ID and MBP constituted the main reason for systematic and frequent consultations.

Treatment

This third main category covers the two choices the GP must make in trying to solve the patient's medical or mental health problem: to treat the patient or refer to a specialist. The participants expressed insecurity about how to treat and what to do with these patients. They described types and possibilities when they wanted to treat the patient themselves following these justifications: i) lack of confidence that a specialist would do the best job with these patients or ii) they believed the referral would be refused by the specialists' health services. This participant illustrates the lack of confidence in specialist services, and trust in own competence:

> *I have to call a random chief doctor at the local psychiatric institution, because that is what the habilitation services relies on… then I think I will do this better by myself. (GP #5)*

There were descriptions of all types of treatment, including check for somatic reasons for restlessness, behaviour modification, environmental actions and medical treatment. When the participants' referred these patients to specialist health services for their MBP, it was mainly for diagnostic work or medication queries. It was more common for the GPs to mention the name of a specialist rather than a specialist department.

> *If I wanted to refer a patient with these problems, NN was the person. (GP #3)*

> *NN2, a psychiatrist with long experience, is easy to turn to, because he provides good answers to my questions. (GP #8)*

Some of the GPs interviewed had created a private system to ensure systematic follow-up: prescribing medication over the short term and developing exclusive lists with patient data and consultation frequency.

Evaluation and continuing treatment

This fourth main category constitutes a cluster of descriptions covering collaboration, evaluation of treatment effects and routines for follow-up consultations. The participants reported their experiences with collaborative partners – particularly how they evaluated the effects of psychotropic medication.

This group of patients nearly always involves one or more collaborative partners. There were descriptions of meetings with parents, community mental health workers, psychiatrists, psychologists and nursing home employees, but they differed in type, in the frequency of the GPs' attendance and in the priority they placed on them.

> *I try to attend every primary meeting with collaborative partners. (GP #9)*

> *I am not often called in to primary meetings. I am, in a few cases, where medical issues are central. (GP #7)*

The GPs usually found meetings with collaborators useful, despite the fact that most of these meetings dealt with issues far from the GPs' areas of expertise. They also described meetings in which specific parts were structured towards their attendance. The feeling of being left alone was mentioned by several participants, but one participant was particularly clear about it:

> *I feel really alone on this topic with these patients. I don't really know what to do. (GP #10)*

The participants admit facing challenges in evaluating the effects of psychotropic medication. Some argued for systematic evaluation of and specific feedback on their patients' behaviour by parents or health care workers, in order to assess the effect of medication:

> *I need observations and detailed feedback. There's no point in continuing a treatment if it isn't effective. Systematic feedback is the required way of working. (GP #7)*

Others wanted a standard feedback sheet:

> *Then you can have a summary over a longer time perspective, rather than some random reports. But I don't know where to get these schemes. (GP #10)*

As schemes or more objective feedback forms were not often provided, the participants were forced to rely upon normative assessments provided by accompanying health workers or parents.

DISCUSSION

Summary of main findings

The results in this study highlight the complexity of providing GP services to people with ID and MBP. The GPs interviewed in this study were strategically selected and were expected to have above-average engagement and competence with this patient group. Evidence-based medicine requires a combination of clinical expertise, best available external evidence and individual patient needs and choices.[24] The competence of the participants in this study is generally experience-based on this topic and therefore characterised by individual opinions and ways of working. It is noteworthy that our participants provided examples of people with ID that they had met in private settings and told us how they found these experiences relevant for their practice with this patient group.

Strengths and limitations of the study

The participants in this study were strategically selected, thereby representing a relatively homogenous group. This situation creates an obvious threat to external validity, and may limit the generalisation of our results. Nevertheless the interviewees revealed diverse opinions and descriptions of their handling of ID patients with MBP, thereby strengthening our impression

that this is an important research topic, albeit rarely investigated or highlighted in national or international settings. Everyone in our research group has read and analysed the transcripts and independently noted meaningful units. The group comprises researchers and clinicians from several areas, thereby limiting the threat of a subjective finding with idiosyncratic perspectives and limited objective value. Our findings can be transferred to clinical situations and can provide a good starting point for further research in the field.

Comparison with existing literature

There is no hard evidence for the necessity and efficacy of using psychotropic medication for treating MBP in people with ID.[25-27] The fact that none of the GPs interviewed could mention any scientific paper that addresses this problem supports the finding that this as an experience-based field, in which doctors rely on general competence valid for people without ID. This is a noteworthy result, especially given the assumption that 70% of psychotropic medication to this patient group is prescribed by the GP alone, without collaboration with a psychiatrist.[28,29]

Implications for future research and clinical parctice

The results demonstrate a major challenge to treatment of MBP in this patient group: None of the participants was sure how to treat these patients themselves, yet they were unsure where to refer their patients if they found the situation too complicated for primary health care treatment alone. They tended to distrust specialist health services. In some areas of the county, the GPs mentioned a local hospital psychiatrist, and other participants mentioned specific persons with whom they could collaborate. All in all, these statements serve to underline the importance of knowledge and information exchange between potential collaborative partners.

Our study shows that GPs' handling of patients with ID and MBP is primarily based upon experience-based knowledge – as told explicitly and as demonstrated through individual descriptions of handling and treatment. The GPs' opinions about their handling of ID patients is based on their own experience with this patient group, and with their general competence related to patients without ID. Attention should be focused on the ways in which medical training and post-graduate education can fill the competence gap, to ensure that this field becomes evidence-based rather than merely experience-based.

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Competing interests

All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; and no other relationships or activities that could appear to have influenced the submitted work.

Ethics approval

The Norwegian regional committee for medical research approved this study.

Contributors

TF contributed to acquisition of data, transcription, analysing data, drafting and critical revision of the article and approval of the final version. ORH, LJD and LL contributed to the design of the study, analysing data, critical revision of the article and approval of the final

version. KK participated in the interviews, analysing data, critical revision of the article and approval of the final version.

Data sharing

No additional data available.

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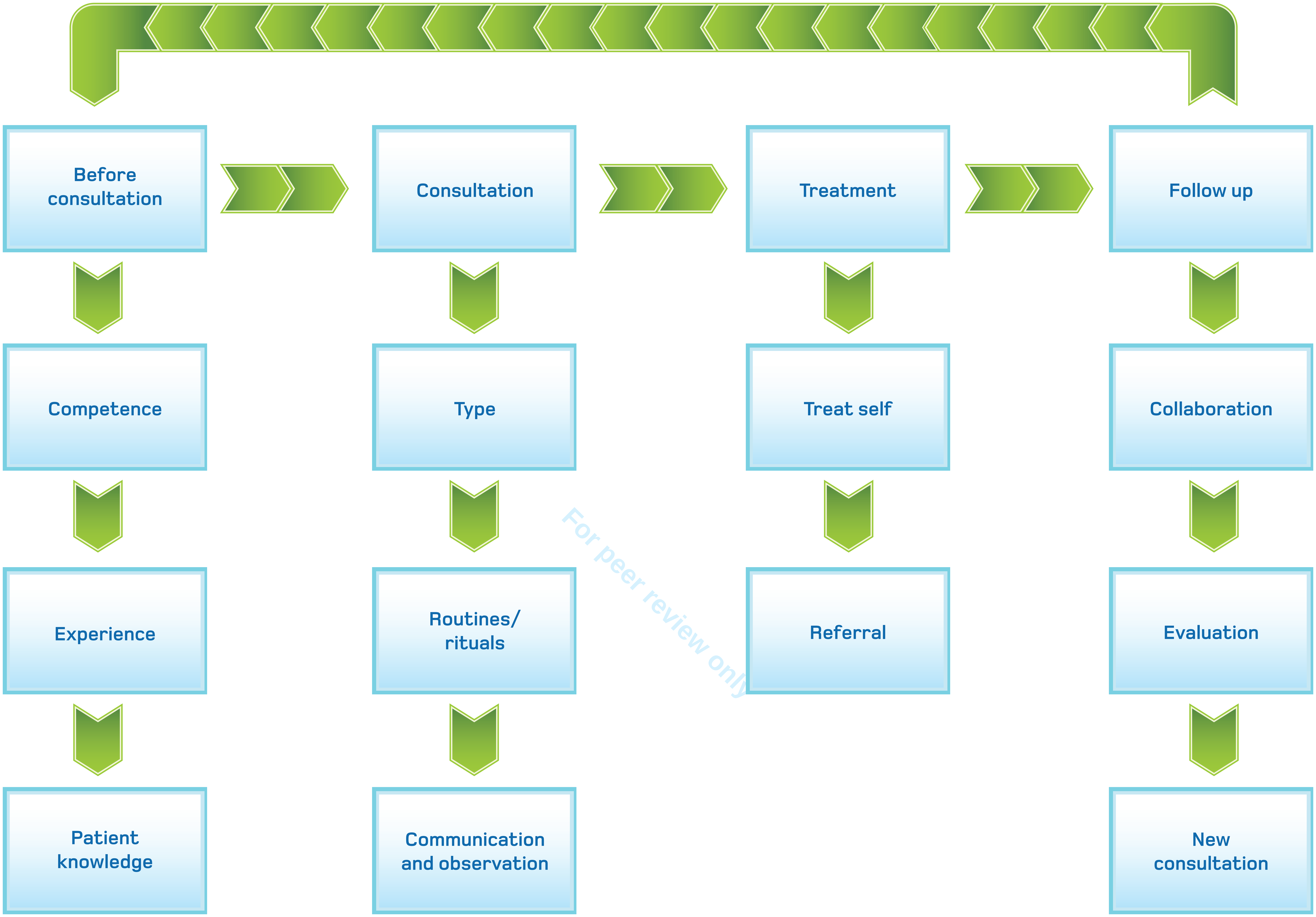
Before consultation
Competence
Experience
Patient knowledge
Consultation
Type
Routines/ rituals
Communication and observation
Treatment
Treat self
Referral
Follow up
Collaboration
Evaluation
New consultation

Research check list - Fredheim et al. 2012

Domain 1: Research team and reflexivity

Personal characteristics

1. Interviewer/facilitator 1:	Terje Fredheim
2. Credentials:	MSc, Master of Learning in Complex Systems
3. Occupation:	PhD-student
4. Gender:	Male
5. Experience and training:	Educated in and have participated in earlier qualitative and quantitative research

1. Interviewer/facilitator 2:	Kari Kjønsberg
2. Credentials:	Reg. nurse, MMHC
3. Occupation:	Reg. nurse specialised in mental health care.
4. Gender:	Female
5. Experience and training:	educated in and have participated in different earlier qualitative health research studies.

Relationship with participants

6. Relationship established: There was no relationship prior to study commencement.
7. Participant knowledge of the interviewer: They were informed about researchers` professional background and interest in the project.
8. Interviewer characteristics: The interviewers` connection with specialised health care may be regarded as bias, but was considered as a minor problem. However the interviewers waited until the interview was over until they presented detailed information about prior experiences and information relevant for the topic.

Domain 2: Study design

Theoretical frame work

9. Methodological orientation and theory: The study relies on a phenomenological approach with content analysis and systematic text condensation as the main method in analysing data.

Participant selection

10. Sampling: Names of possible participants were given the interviewers from a senior psychiatrist retired after decades in habilitation services. Our research group regarded this psychiatrist to be the best source to help us find the sample of participants we were looking for. The interviewers then recruited strategically from this list to represent different gender, age, diagnosis and location (rural or city).
11. Method of approach: Participants were first contacted by letter. Two or three days after likely retrieval of the letter, possible participants were contacted by telephone. Information was given and request made, and appointment made with those who were positive.
12. Sample size: Ten participants were interviewed.
13. Non-participation: Five persons refused/hesitated to participate. No drop-outs. The reason for non-participation was not asked for.

Setting

14. Setting of data collection: All interviews were conducted in the participants` office or nearby meeting room.
15. Presence of non-participants: None.
16. Description of sample: Seven males and three females were interviewed. They represented various age and location (city/rural).

Data collection
17. Interview guide: A guide with themes and main questions was provided by the researchers and discussed with the supervisors. Also a checklist was used to get more information on topics that seemed important or topics not mentioned by the participant. No pilot was tested.
18. Repeat interviews: Repeated interviews were not used. Participants were encouraged to contact the interviewers if they wanted to add something and one of them made contact by telephone to give some more information.
19. Audio/visual recording: Audio recording was used to collect data.
20. Field notes: The two interviewers made field notes during the interviews, and immediately after each interview.
21. Duration: Interviews lasted 47 – 81 minutes.
22. Data saturation: Saturation and was discussed in the research group after the tenth interview had been conducted and was then regarded as satisfactory. We were open to the fact that new themes and important information could appear, but regarded the data material to contain breath and depth for the topic investigated.
23. Transcripts returned: Transcripts were not returned to participants for comment or corrections.

Domain 3. Analysis and findings

Data analysis
24. Number of data coders: All five in the research group read the complete transcript. One of the interviewers presented identified meaningful units and themes derivated from the material and they were discussed in the research group.
25. Description of the coding tree: The coding tree is illustrated with a figure of major and minor themes.
26. Derivation of themes: Themes emerged from the data.
27. Software: No additional software was used.
28. Participant checking: Participants were offered feedback on the findings. Five of them expressed a request for feedback when the material had been accepted for publication.

Reporting
29. Quotations presented: Participant quotations were used to illustrate findings. Quotations are not identified in this paper due to a small number of participants.
30. Data and findings consistent: The themes developed by the researcher(s) were logically consistent and reflective of the data.
31. Clarity of major themes: The major themes are described in the article, and reflect the research question.
32. Clarity of minor themes: Minor themes are described in the article, and reflect meaningful units. Diverse cases are described where necessary.

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Terje Fredheim[1,4]*, Ole R Haavet[4] Lars J Danbolt[1,3], Kari Kjønsberg[1], Lars Lien[1,2],

[1]Centre for Psychology of Religion, Innlandet Hospital Trust (SIHF), Hamar, Norway

[2] Faculty of public health, University College of Hedmark, Elverum, Norway

[3]Norwegian School of Theology, Oslo, Norway

[4]Department of General Practice, University of Oslo, Oslo, Norway

* Corresponding Author:

Terje Fredheim, Religionspsykologisk Senter, Postboks 68, N-2312 Ottestad

E-mail: terje.fredheim@sykehuset-innlandet.no

Phone: 0047 - 41219155

Article summary

Article focus

- The aim of this study was to investigate the general practitioners (GPs) experiences in handling people with intellectual disabilities and mental/behavioural problems (MBP) in order to identify factors related to high quality services, important areas for improvement and suggest fields for further exploration.

Key messages

- This study shows that GPs have different opinions on central subjects in providing high quality services to people with ID and MBP.
- Even GPs with an assumed high competence and engagement in this patient group, lack evidence based knowledge and base their actions on experience based practice.
- GPs are concerned about the competence in specialist departments when it comes to treatment of MBP in people with ID

Strenghts and limitations in this study

- Participants were of both genders, from several localities and had a broad range of patients with ID and MBP.
- As far as we know, this is the only study that has addressed GPs experiences with people with ID and MBP.
- Although data across participants were found sufficient, a small group of participants were interviewed.

Abstract

Objectives To investigate general practitioners' (GPs) experiences in managing people with intellectual disabilities (ID) and mental and behavioural problems (MBP).

Design Qualitative study using in-depth interviews.

Setting General practice in Hedmark County, Norway.

Participants 10 GPs were qualitatively interviewed about their professional experience regarding people with ID and MBP. Data were analysed by all authors using systematic text condensation.

Results The participants' knowledge was primarily experience based and collaboration with specialists seemed to be individual rather than systemic. The GPs provided different meanings for referral, treatment, collaboration, regular health checks and home visits.

Conclusions GPs are in a position to provide evidence-based and individual treatment for both psychological and somatic problems among people with ID. This potential is not yet fully exploited. The findings in this study provide useful information for further research in the field.

Introduction

People with intellectual disabilities (ID) are particularly vulnerable to health problems and experience difficulties in meeting their health care needs.[1-7] Two recent attempts provide a focus to this challenge: a consensus manifesto by the European Association of Intellectual Disability Medicine[8] and an independent inquiry on a request from the British Secretary of State for Health.[9] These reports share the goal of improving health care services for people with ID, but the extent to which their recommendations have been implemented remains dubious. A guideline provides Canadian primary care professionals with practical recommendations based on evidence and current knowledge, to address the particular health needs of people with ID. [10] In Norway, an internet course from the Norwegian Medical Association, have since 2007 been available to expand the knowledge on patients with ID.

A recent meta-analysis has shown that the prevalence of ID is approximately 1%.[11] Prevalence of mental health problems among people with ID vary in different studies from 14% to 60% and can be difficult to identify and diagnose.[12] There is considerable overlap between mental health problems and challenging behaviour[13,14]; these two complications are often inseparable, suggesting that there is little to gain from distinguishing between them when trying to identify implications for health workers. To detect and treat people with ID and mental and behaviour problems (MBP) is a test of the competence of the general practitioner (GP). Doctors specialising in general practice acquire knowledge about the early and general presentation of diseases, and early treatment and follow-up of chronic disease. GPs play a central role because of their familiarity with other primary health care services, as gate-keepers to specialist health care and in evaluating treatment and cooperate with the patient, family and other service providers.[15-18]

Each Norwegian GP has 5 to 10 patients with ID on their list. Some of these patients will have MBP, which potentially influences their physical health, including poor diet; erratic compliance with medication; and behaviour that can affect physical health, creating the need for close care and structure in health services.[19] A qualitative study have identified areas of discomfort when it comes to proper educational training for GPs, to meet the health needs of people with ID. [20]

The importance of closely monitored care and high-quality health services to meet the challenge of inequality in health services for people with ID have provided the focus for several papers.[1,3,5,6,21] There is however few studies that have looked at the way GPs are working with patients with ID and MBP. The aim of our research was to explore the experiences, attitudes and perceived role and competence of GPs providing health services to people with ID, with a special focus on people with ID and MBP.

METHODS

A qualitative method

We opted for a qualitative approach, in order to obtain more detailed descriptions of the GPs' experiences serving people with ID and MBP. In-depth interviews are suitable in inquiring about the GP's experiences, facilitating a deeper understanding of their opinions and attitudes.[22,23] We preferred open interviews to focus on each participant's descriptions and experiences, and bringing narratives into the method, by giving participants the opportunity to provide meaning to their responses.

Participants

Data were drawn from a total of 10 interviews with 10 participating GPs aged 41 to 64 (table 1). Participants were chosen following recommendations from an acknowledged senior psychiatrist with more than 30 years of experience with ID patients in collaboration with GPs in Hedmark County. There are 173 GPs in Hedmark, and the senior psychiatrist considered 25 of them to have more than the usual level of experience with ID patients and a relatively large number of ID patients on their list. A letter was sent to 15 of these GPs, purposefully selected with regard to geographical location and gender. 10 GPs were able to participate, 3 GPs refused to participate, and 2 GPs did not respond. Participation in this study was voluntary, and each participant signed an informed consent form, and was informed of their right to withdraw from the study at any time, without further explanation.

TABLE 1

Participant number	Age	Gender	Location	Total number of patients	Approximate number of ID patients	Reported number. of ID patients with psychiatric/ behavioural challenge
1	58	F	Rural	950	6	2
2	61	M	City	1200	3	2
3	60	M	Rural	800	14	4
4	64	M	City	2500	20	10
5	60	M	Rural	750	15	6
6	61	M	City	1000	5	?
7	60	M	City	1100	30	20
8	42	F	Rural	850	7	3
9	59	M	Rural	1000	12	6
10	41	F	Rural	1300	10	5

Participants' number, age, gender, location, total number of patients, approximately number of patients with ID, and reported number of ID-patients with mental or behavioural problems

Setting

All 10 interviews were conducted in the GPs' offices, located in Hedmark county, an agricultural county with small towns and a total population of approximately 190 000. The interviews lasted 41–81 minutes, with a mean of 57 minutes. Interviews were conducted from

October to November 2011 and were audio recorded. All but one interview was conducted by two of the authors (TF and KK), and there were no former relationship between the participants and the interviewers. The interviews were planned, the participants were prepared on the topic and had allocated time for the interview. The interview consisted of open-ended questions based on an interview guide with two main questions:

1. What are your experiences with ID patients who have additional mental health problems and/or challenging behaviour?
2. What do you think is the GP's role for these patients?

The additional checklist was used to gather information that was otherwise missing or to provide greater depth or breadth to incomplete information. Follow-up questions were taken from a list of keywords; number of patients in the GP's patient group, collaborative partners, regular health checks, specific training on the topic, perceived knowledge, knowledge of evidence based literature on the topic and attitude towards psychotropic treatment of people with ID.

Analysis

The interviewers made field notes with the participants' frequently used words, phrases and other statements requiring follow-up. Pauses, engagement, laughter and gestures were also noted, and the field notes were used in addition to the total transcripts. The 10 interviews generated approximately 119 pages of single-spaced text. Analysis of transcripts was conducted using systematic text condensation.[22,24,25] The first author read the transcripts several times to obtain a sense of the whole. The other authors independently read the transcripts and identified meaningful units, themes and subthemes, trying to capture the "essential expression". These findings were discussed among the authors.

RESULTS

During the interview, GPs described their experiences, consultations and collaboration with a variety of relatives and professionals. Case presentations included descriptions of ID patients with complex medical, psychiatric and behavioural challenges. GPs shared examples of what kind of challenges they were faced with, managing these patients. It could be a patient with Down syndrome, psychiatric illness and hard regulated diabetes. Other patients could be aggressive both verbally and physically and not willing to participate in tests in a typical consultation at the doctor's office. Some of the patients lived alone with little community services, and were having a lifestyle with several potential harmful traits, like heavily smoking, alcohol drinking or eating disorders, and limited cognitive resources to understand the consequences of their actions.

As a model of analysis, the process of a consultation emerged from the material as the best description of the GPs' experiences with this group of patients (figure 1). This model illustrates a GP's pathway through a consultation with four main categories: basis for decisions, consultation, treatment and follow-up.

Figure 1 approximately here

Basis for decisions

The main category, *basis for decisions,* epitomizes the GP's knowledge and experience in the context of the patient group and describes their medical education, experiences, courses and relevant post-graduate education on this topic. The GPs described limited training in patients with ID from their medical school or post-graduate courses. On direct question, none of the GPs' had knowledge of The Medical Associations internet-based course on the topic.

> *The Norwegian Medical Association arranges a lot of courses, but I have until today's date never seen a course on this topic. (GP #6)*

When the GPs' were directly asked on what basis they treated these patients there was no mention of articles, books or peer-reviewed journals on the topic:

> *I think… those medications that I am used to prescribing, and that I know are effective in any or another way, I will use them as a common guideline. (GP #1)*

> *I have common knowledge about patients and psychiatry. I have a large number of patients and I have years of experience. (GP #4)*

> *It might be revealing, but I use common sense and my own experiences. (GP #9)*

> *I haven't read any literature on this theme, but I have learned some in collaborating with Habilitation services. (GP #6)*

Knowledge of the patients' background and continuity in the relationship between patient and physician were seen as key issues in providing the best service. Furthermore these GPs saw the advantage of being a family doctor, improving the relationship to the patients allowing the GP to make a better job of evaluating the biological, psychological and social strengths of the patients. As one participant said:

> *The family will be a support system for the patient anyway, so l see this as a great advantage. (GP #6)*

> *A patient of me, his sister and sister's child are my patients. His sister has been here, lying on the bench pregnant. He knows this, and we talk a little about it. It seems to make him more comfortable and familiar with the situation when he knows I am helping more of his family as well. I can measure his blood pressure and do blood samples, some thing he was not able to do at his former GP. (GP #1)*

A key finding in this category is that most of the treatment is founded on experience-based knowledge. The material was rich in descriptions of patient histories, organisational system changes and historical events in the ID health care service, together with private memories from childhood or random meetings with people with intellectual disability. Because experiences are individual, there were many different stories, opinions and points of view.

> *Already in primary school I went to a school where people with ID were integrated. Having contact with people with ID has never been strange or unfamiliar for me. (GP #8)*

Consultation

The second main category, *consultation*, covers type of consultation, communication and individual routines or rituals by either the GP or the patient. First there are descriptions of various types of consultations which can occur in either the office or the patient's home: acute consultation, planned evaluations of treatment and prescriptions, and health checks. The GPs varied in their opinions about the benefits and possibilities of seeing the patient at home, as quotes from these two doctors illustrate:

> *Home visits are soon to become a closed chapter in general practice, but with these patients I find it necessary to do home visits. Then I can see with my own eyes how things appear at home (GP #5).*

> *They need to be observed and… it is not always easy for a GP to be able to observe. A GP should stay in the office and be available for patients (GP #4).*

Furthermore the GPs have different opinions about the benefits and possibilities of regular health checks for this patient group. Lack of standard guidelines opens the door for individual solutions and a variety of explanations. One participant highlighted this patient group as bad requesters of health care, requiring closer follow-up:

> *We may not be optimally good at this, but we try to do it once a year, and that is about were it ends. Some have a health problem that leads to more frequent consultations; in those cases a yearly health control is less important. But in general these are patients who don't tend to promote themselves. (GP #9)*

There were descriptions of patients who went through special routines and rituals in their GP's office. It seemed to be important for the relationship between the GP and the patient that these routines be followed; the patient tended to be calmer allowing the doctor to undertake the necessary investigations. As one participant said:

> *He is sitting here, takes a glass of water, sits down again and drinks some water. Sometimes I am able to check his blood pressure and do blood tests. He was not able to do that with his previous GP (GP #1).*

Communication and observation is another cluster of experiences in this category. Some of these patients are obviously anxious about a consultation, and all GPs said that their focus was on the patient, communicating directly with the ID patients, even though they were accompanied by others. If something could not be done because of unwillingness or restlessness, they did not push the patient, but booked another appointment in the near future.

Our participants argued that their patients' should be accompanied by someone who knows the patient, their medical history and the reason for the consultation. Yet patients with communication problems were sometimes accompanied to the doctor's office by health workers with limited knowledge of the patient. Because GPs must rely on information from accompanying persons, they would sometimes send the patient home with a new appointment. As one participant said:

> *It is essential that we have confidence in the information we are given. And that it is not exaggerated, hyped or trivialized, but is a sober description that it is possible for me as a GP to navigate towards (GP #7).*

Some participants were more likely to use systematic consultations and follow-up, especially if the patient had chronic somatic problems. Nevertheless, the somatic problem, rather than the ID and MBP constituted the main reason for systematic and frequent consultations.

Treatment

This third main category covers the choice the GP must make in trying to solve the patient's medical or mental health problem: to treat the patient or refer to a specialist. The participants expressed insecurity about how to treat and what to do with these patients. They described types and possibilities when they wanted to treat the patient themselves following these justifications: i) lack of confidence that a specialist would do the best job with these patients or ii) they believed the referral would be refused by the specialists' health services. This participant illustrates the lack of confidence in specialist services, and trust in own competence:

> *I have to call a random chief doctor at the local psychiatric institution, because that is what the habilitation services relies on… then I think I will do this better by myself. (GP #5)*

There were descriptions of all types of treatment, including check for somatic reasons for restlessness, behaviour modification, environmental actions and medical treatment. When the participants' referred these patients to specialist health services for their MBP, it was mainly for diagnostic work or medication queries. It was more common for the GPs to mention the name of a specialist rather than a specialist department.

> *If I wanted to refer a patient with these problems, NN was the person. (GP #3)*

> *NN2, a psychiatrist with long experience, is easy to turn to, because he provides good answers to my questions. (GP #8)*

Some of the GPs interviewed had created a private system to ensure systematic follow-up: prescribing medication over the short term and developing exclusive lists with patient data and consultation frequency.

Evaluation and continuing treatment

This fourth main category constitutes a cluster of descriptions covering collaboration, evaluation of treatment effects and routines for follow-up consultations. The participants reported their experiences with collaborative partners – particularly how they evaluated the effects of psychotropic medication.

A patient with ID and MBP nearly always involves one or more collaborative partners. Interdisciplinary meetings were described as useful if the GPs had the opportunity to participate. The GPs were not sure if they were invited to all meetings, but had the impression that their attendance and competence was wanted. There were descriptions of meetings with parents, community mental health workers, psychiatrists, psychologists and nursing home employees, but they differed in type, in the frequency of the GPs' attendance and in the priority they placed on them.

> *I try to attend every primary meeting with collaborative partners. (GP #9)*

> *I am not often called in to primary meetings. I am, in a few cases, where medical issues are central. (GP #7)*

The GPs that attended usually found meetings with collaborators useful, despite the fact that most of these meetings dealt with issues far from the GPs' areas of expertise. Some described meetings in which specific parts were structured towards their attendance, and this was told to lowering the barriers of GP attendance. Even though the GPs met a group of several collaborators facing the challenges of a patient, they felt alone in issues regarding medical questions for patients with ID and MBP. The feeling of being left alone was mentioned by several participants, but one participant was particularly clear about it:

> *I feel really alone on this topic with these patients. I don't really know what to do. (GP #10)*

The participants admit facing challenges in evaluating the effects of psychotropic medication. Some argued for systematic evaluation of and specific feedback on their patients' behaviour by parents or health care workers, in order to assess the effect of medication:

> *I need observations and detailed feedback. There's no point in continuing a treatment if it isn't effective. Systematic feedback is the required way of working. (GP #7)*

Others wanted a standard feedback sheet:

> *Then you can have a summary over a longer time perspective, rather than some random reports. But I don't know where to get these schemes. (GP #10)*

As schemes or more objective feedback forms were not often provided, the participants were forced to rely upon normative assessments provided by accompanying health workers or parents.

DISCUSSION

Summary of main findings

The results in this study highlight the complexity of providing GP services to people with ID and MBP. The GPs interviewed in this study were strategically selected and were expected to have above-average engagement and competence with this patient group. Evidence-based medicine requires a combination of clinical expertise, best available external evidence and individual patient needs and choices.[26] The competence of the participants in this study is generally experience-based on this topic and therefore characterised by individual opinions and ways of working. The participants described limited education on ID issues, and none could refer to any scientific article, book or report on this topic. Even though there has been a course directed to GPs on ID patients, with a subcategory on MBP, none of the participants had attended it. This study implies that GPs with more than usual level of experience and interest in patients with ID and MBP, mainly relies on experience based knowledge, and have limited knowledge of articles, guidelines, reports or books on this topic. The fact that challenges managing patients with ID and MBP nearly is taught in medical school and the only course available is an internet course may contribute to the understanding of limited evidence based knowledge among the participants. In addition, our results imply that this topic is rarely mentioned in scientific papers or on conferences and courses with GP participation.

Strengths and limitations of the study

The participants in this study were strategically selected, thereby representing a relatively homogenous group. This situation creates an obvious threat to external validity, and may limit the generalisation of our results. Nevertheless the interviewees revealed diverse opinions and descriptions of their managing of ID patients with MBP, thereby strengthening our impression

that this is an important research topic, albeit rarely investigated or highlighted in national or international settings. Everyone in our research group has read and analysed the transcripts and independently noted meaningful units. The group comprises researchers and clinicians from several areas, thereby limiting the threat of a subjective finding with idiosyncratic perspectives and limited objective value. Our findings can be transferred to clinical situations and can provide a good starting point for further research in the field.

Comparison with existing literature

There is no hard evidence for the necessity and efficacy of using psychotropic medication for treating MBP in people with ID.[27-30] The fact that none of the GPs interviewed could mention any scientific paper that addresses this problem supports the finding that this as an experience-based field, in which doctors rely on general competence valid for people without ID. This is a noteworthy result, especially given the assumption that 70% of psychotropic medication to this patient group is prescribed by the GP alone, without collaboration with a psychiatrist.[31,32] Furthermore the results are in line with findings from another qualitative study that addressed the educational needs of family physicians of people with ID, pointing out a need for modifications of their education.[20]

Implications for future research and clinical practice

The results demonstrate a major challenge to treatment of MBP in people with ID: None of the participants was sure how to treat these patients themselves, yet they were unsure where to refer their patients if they found the situation too complicated for primary health care treatment alone. They tended to distrust specialist health services. In some areas of the county, the GPs mentioned a local hospital psychiatrist, and other participants mentioned specific persons with whom they could collaborate. All in all, these statements serve to underline the importance of knowledge and information exchange between potential collaborative partners.

Our study shows that GPs' managing of patients with ID and MBP is primarily based upon experience-based knowledge – as told explicitly and as demonstrated through individual descriptions of managing and treatment. The GPs' opinions about working with ID patients is based on their own experience with this patient group, and with their general competence related to patients without ID. Attention should be focused on the ways in which medical training and post-graduate education can fill the competence gap, to ensure that this field becomes evidence-based rather than merely experience-based. As a start, the clinical guidelines from Canada mention some issues regarding people with ID and MBP[10], and should be marketed for GPs working with these patients.

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Competing interests

All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; and no other relationships or activities that could appear to have influenced the submitted work.

Ethics approval

The Norwegian regional committee for medical research approved this study.

Contributors

TF contributed to acquisition of data, transcription, analysing data, drafting and critical revision of the article and approval of the final version. ORH, LJD and LL contributed to the design of the study, analysing data, critical revision of the article and approval of the final version. KK participated in the interviews, analysing data, critical revision of the article and approval of the final version.

Data sharing

No additional data available.

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Intellectual disability and mental health problems: a qualitative study of general practitioners' views

Terje Fredheim[1,4]*, Ole R Haavet[4] Lars J Danbolt[1,3], Kari Kjønsberg[1], Lars Lien[1,2],

[1]Centre for Psychology of Religion, Innlandet Hospital Trust (SIHF), Hamar, Norway

[2] Faculty of public health, University College of Hedmark, Elverum, Norway

[3]Norwegian School of Theology, Oslo, Norway

[4]Department of General Practice, University of Oslo, Oslo, Norway

* Corresponding Author:

Terje Fredheim, Religionspsykologisk Senter, Postboks 68, N-2312 Ottestad

E-mail: terje.fredheim@sykehuset-innlandet.no

Phone: 0047 - 41219155

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- This study shows that GPs have different opinions on central subjects in providing high quality services to people with ID and MBP.
- Even GPs with an assumed high competence and engagement in this patient group, lack evidence based knowledge and base their actions on experience based practice.
- GPs are concerned about the competence in specialist departments when it comes to treatment of MBP in people with ID

Strenghts and limitations in this study

- Participants were of both genders, from several localities and had a broad range of patients with ID and MBP.
- As far as we know, this is the only study that has addressed GPs experiences with people with ID and MBP.
- Although data across participants were found sufficient, a small group of participants were interviewed.

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Objectives To investigate general practitioners' (GPs) experiences in managing people with intellectual disabilities (ID) and mental and behavioural problems (MBP).

Design Qualitative study using in-depth interviews.

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Participants 10 GPs were qualitatively interviewed about their professional experience regarding people with ID and MBP. Data were analysed by all authors using systematic text condensation.

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Conclusions GPs are in a position to provide evidence-based and individual treatment for both psychological and somatic problems among people with ID. This potential is not yet fully exploited. The findings in this study provide useful information for further research in the field.

Introduction

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A recent meta-analysis has shown that the prevalence of ID is approximately 1%.[11] Prevalence of mental health problems among people with ID vary in different studies from 14% to 60% and can be difficult to identify and diagnose.[12] There is considerable overlap between mental health problems and challenging behaviour[13,14]; these two complications are often inseparable, suggesting that there is little to gain from distinguishing between them when trying to identify implications for health workers. To detect and treat people with ID and mental and behaviour problems (MBP) is a test of the competence of the general practitioner (GP). Doctors specialising in general practice acquire knowledge about the early and general presentation of diseases, and early treatment and follow-up of chronic disease. GPs play a central role because of their familiarity with other primary health care services, as gate-keepers to specialist health care and in evaluating treatment and cooperate with the patient, family and other service providers.[15-18]

Each Norwegian GP has 5 to 10 patients with ID on their list. Some of these patients will have MBP, which potentially influences their physical health, including poor diet; erratic compliance with medication; and behaviour that can affect physical health, creating the need for close care and structure in health services.[19] A qualitative study have identified areas of discomfort when it comes to proper educational training for GPs, to meet the health needs of people with ID. [20]

The importance of closely monitored care and high-quality health services to meet the challenge of inequality in health services for people with ID have provided the focus for several papers.[1,3,5,6,21] There is however few studies that have looked at the way GPs are working with patients with ID and MBP. The aim of our research was to explore the experiences, attitudes and perceived role and competence of GPs providing health services to people with ID, with a special focus on people with ID and MBP.

METHODS

A qualitative method

We opted for a qualitative approach, in order to obtain more detailed descriptions of the GPs' experiences serving people with ID and MBP. In-depth interviews are suitable in inquiring about the GP's experiences, facilitating a deeper understanding of their opinions and attitudes.[22,23] We preferred open interviews to focus on each participant's descriptions and experiences, and bringing narratives into the method, by giving participants the opportunity to provide meaning to their responses.

Participants

Data were drawn from a total of 10 interviews with 10 participating GPs aged 41 to 64 (table 1). Participants were chosen following recommendations from an acknowledged senior psychiatrist with more than 30 years of experience with ID patients in collaboration with GPs in Hedmark County. There are 173 GPs in Hedmark, and the senior psychiatrist considered 25 of them to have more than the usual level of experience with ID patients and a relatively large number of ID patients on their list. A letter was sent to 15 of these GPs, purposefully selected with regard to geographical location and gender. 10 GPs were able to participate, 3 GPs refused to participate, and 2 GPs did not respond. Participation in this study was voluntary, and each participant signed an informed consent form, and was informed of their right to withdraw from the study at any time, without further explanation.

TABLE 1

Participant number	Age	Gender	Location	Total number of patients	Approximate number of ID patients	Reported number. of ID patients with psychiatric/ behavioural challenge
1	58	F	Rural	950	6	2
2	61	M	City	1200	3	2
3	60	M	Rural	800	14	4
4	64	M	City	2500	20	10
5	60	M	Rural	750	15	6
6	61	M	City	1000	5	?
7	60	M	City	1100	30	20
8	42	F	Rural	850	7	3
9	59	M	Rural	1000	12	6
10	41	F	Rural	1300	10	5

Participants' number, age, gender, location, total number of patients, approximately number of patients with ID, and reported number of ID-patients with mental or behavioural problems

Setting

All 10 interviews were conducted in the GPs' offices, located in Hedmark county, an agricultural county with small towns and a total population of approximately 190 000. The interviews lasted 41–81 minutes, with a mean of 57 minutes. Interviews were conducted from

October to November 2011 and were audio recorded. All but one interview was conducted by two of the authors (TF and KK), and there were no former relationship between the participants and the interviewers. The interviews were planned, the participants were prepared on the topic and had allocated time for the interview. The interview consisted of open-ended questions based on an interview guide with two main questions:

1. What are your experiences with ID patients who have additional mental health problems and/or challenging behaviour?
2. What do you think is the GP's role for these patients?

The additional checklist was used to gather information that was otherwise missing or to provide greater depth or breadth to incomplete information. Follow-up questions were taken from a list of keywords; number of patients in the GP's patient group, collaborative partners, regular health checks, specific training on the topic, perceived knowledge, knowledge of evidence based literature on the topic and attitude towards psychotropic treatment of people with ID.

Analysis

The interviewers made field notes with the participants' frequently used words, phrases and other statements requiring follow-up. Pauses, engagement, laughter and gestures were also noted, and the field notes were used in addition to the total transcripts. The 10 interviews generated approximately 119 pages of single-spaced text. Analysis of transcripts was conducted using systematic text condensation.[22,24,25] The first author read the transcripts several times to obtain a sense of the whole. The other authors independently read the transcripts and identified meaningful units, themes and subthemes, trying to capture the "essential expression". These findings were discussed among the authors.

RESULTS

During the interview, GPs described their experiences, consultations and collaboration with a variety of relatives and professionals. Case presentations included descriptions of ID patients with complex medical, psychiatric and behavioural challenges. GPs shared examples of what kind of challenges they were faced with, managing these patients. It could be a patient with Down syndrome, psychiatric illness and hard regulated diabetes. Other patients could be aggressive both verbally and physically and not willing to participate in tests in a typical consultation at the doctor's office. Some of the patients lived alone with little community services, and were having a lifestyle with several potential harmful traits, like heavily smoking, alcohol drinking or eating disorders, and limited cognitive resources to understand the consequences of their actions.

As a model of analysis, the process of a consultation emerged from the material as the best description of the GPs' experiences with this group of patients (figure 1). This model illustrates a GP's pathway through a consultation with four main categories: basis for decisions, consultation, treatment and follow-up.

Figure 1 approximately here

Basis for decisions

The main category, *basis for decisions,* epitomizes the GP's knowledge and experience in the context of the patient group and describes their medical education, experiences, courses and relevant post-graduate education on this topic. The GPs described limited training in patients with ID from their medical school or post-graduate courses. On direct question, none of the GPs' had knowledge of The Medical Associations internet-based course on the topic.

> *The Norwegian Medical Association arranges a lot of courses, but I have until today's date never seen a course on this topic. (GP #6)*

When the GPs' were directly asked on what basis they treated these patients there was no mention of articles, books or peer-reviewed journals on the topic:

> *I think… those medications that I am used to prescribing, and that I know are effective in any or another way, I will use them as a common guideline. (GP #1)*

> *I have common knowledge about patients and psychiatry. I have a large number of patients and I have years of experience. (GP #4)*

> *It might be revealing, but I use common sense and my own experiences. (GP #9)*

> *I haven't read any literature on this theme, but I have learned some in collaborating with Habilitation services. (GP #6)*

Knowledge of the patients' background and continuity in the relationship between patient and physician were seen as key issues in providing the best service. Furthermore these GPs saw the advantage of being a family doctor, improving the relationship to the patients allowing the GP to make a better job of evaluating the biological, psychological and social strengths of the patients. As one participant said:

> *The family will be a support system for the patient anyway, so l see this as a great advantage. (GP #6)*

> *A patient of me, his sister and sister's child are my patients. His sister has been here, lying on the bench pregnant. He knows this, and we talk a little about it. It seems to make him more comfortable and familiar with the situation when he knows I am helping more of his family as well. I can measure his blood pressure and do blood samples, some thing he was not able to do at his former GP. (GP #1)*

A key finding in this category is that most of the treatment is founded on experience-based knowledge. The material was rich in descriptions of patient histories, organisational system changes and historical events in the ID health care service, together with private memories from childhood or random meetings with people with intellectual disability. Because experiences are individual, there were many different stories, opinions and points of view.

> *Already in primary school I went to a school where people with ID were integrated. Having contact with people with ID has never been strange or unfamiliar for me. (GP #8)*

Consultation

The second main category, *consultation*, covers type of consultation, communication and individual routines or rituals by either the GP or the patient. First there are descriptions of various types of consultations which can occur in either the office or the patient's home: acute consultation, planned evaluations of treatment and prescriptions, and health checks. The GPs varied in their opinions about the benefits and possibilities of seeing the patient at home, as quotes from these two doctors illustrate:

> *Home visits are soon to become a closed chapter in general practice, but with these patients I find it necessary to do home visits. Then I can see with my own eyes how things appear at home (GP #5).*

> *They need to be observed and… it is not always easy for a GP to be able to observe. A GP should stay in the office and be available for patients (GP #4).*

Furthermore the GPs have different opinions about the benefits and possibilities of regular health checks for this patient group. Lack of standard guidelines opens the door for individual solutions and a variety of explanations. One participant highlighted this patient group as bad requesters of health care, requiring closer follow-up:

> *We may not be optimally good at this, but we try to do it once a year, and that is about were it ends. Some have a health problem that leads to more frequent consultations; in those cases a yearly health control is less important. But in general these are patients who don't tend to promote themselves. (GP #9)*

There were descriptions of patients who went through special routines and rituals in their GP's office. It seemed to be important for the relationship between the GP and the patient that these routines be followed; the patient tended to be calmer allowing the doctor to undertake the necessary investigations. As one participant said:

> *He is sitting here, takes a glass of water, sits down again and drinks some water. Sometimes I am able to check his blood pressure and do blood tests. He was not able to do that with his previous GP (GP #1).*

Communication and observation is another cluster of experiences in this category. Some of these patients are obviously anxious about a consultation, and all GPs said that their focus was on the patient, communicating directly with the ID patients, even though they were accompanied by others. If something could not be done because of unwillingness or restlessness, they did not push the patient, but booked another appointment in the near future.

Our participants argued that their patients' should be accompanied by someone who knows the patient, their medical history and the reason for the consultation. Yet patients with communication problems were sometimes accompanied to the doctor's office by health workers with limited knowledge of the patient. Because GPs must rely on information from accompanying persons, they would sometimes send the patient home with a new appointment. As one participant said:

> *It is essential that we have confidence in the information we are given. And that it is not exaggerated, hyped or trivialized, but is a sober description that it is possible for me as a GP to navigate towards (GP #7).*

Some participants were more likely to use systematic consultations and follow-up, especially if the patient had chronic somatic problems. Nevertheless, the somatic problem, rather than the ID and MBP constituted the main reason for systematic and frequent consultations.

Treatment

This third main category covers the choice the GP must make in trying to solve the patient's medical or mental health problem: to treat the patient or refer to a specialist. The participants expressed insecurity about how to treat and what to do with these patients. They described types and possibilities when they wanted to treat the patient themselves following these justifications: i) lack of confidence that a specialist would do the best job with these patients or ii) they believed the referral would be refused by the specialists' health services. This participant illustrates the lack of confidence in specialist services, and trust in own competence:

> *I have to call a random chief doctor at the local psychiatric institution, because that is what the habilitation services relies on… then I think I will do this better by myself. (GP #5)*

There were descriptions of all types of treatment, including check for somatic reasons for restlessness, behaviour modification, environmental actions and medical treatment. When the participants' referred these patients to specialist health services for their MBP, it was mainly for diagnostic work or medication queries. It was more common for the GPs to mention the name of a specialist rather than a specialist department.

> *If I wanted to refer a patient with these problems, NN was the person. (GP #3)*

> *NN2, a psychiatrist with long experience, is easy to turn to, because he provides good answers to my questions. (GP #8)*

Some of the GPs interviewed had created a private system to ensure systematic follow-up: prescribing medication over the short term and developing exclusive lists with patient data and consultation frequency.

Evaluation and continuing treatment

This fourth main category constitutes a cluster of descriptions covering collaboration, evaluation of treatment effects and routines for follow-up consultations. The participants reported their experiences with collaborative partners – particularly how they evaluated the effects of psychotropic medication.

A patient with ID and MBP nearly always involves one or more collaborative partners. Interdisciplinary meetings were described as useful if the GPs had the opportunity to participate. The GPs were not sure if they were invited to all meetings, but had the impression that their attendance and competence was wanted. There were descriptions of meetings with parents, community mental health workers, psychiatrists, psychologists and nursing home employees, but they differed in type, in the frequency of the GPs' attendance and in the priority they placed on them.

> *I try to attend every primary meeting with collaborative partners. (GP #9)*

> *I am not often called in to primary meetings. I am, in a few cases, where medical issues are central. (GP #7)*

The GPs that attended usually found meetings with collaborators useful, despite the fact that most of these meetings dealt with issues far from the GPs' areas of expertise. Some described meetings in which specific parts were structured towards their attendance, and this was told to lowering the barriers of GP attendance. Even though the GPs met a group of several collaborators facing the challenges of a patient, they felt alone in issues regarding medical questions for patients with ID and MBP. The feeling of being left alone was mentioned by several participants, but one participant was particularly clear about it:

> *I feel really alone on this topic with these patients. I don't really know what to do. (GP #10)*

The participants admit facing challenges in evaluating the effects of psychotropic medication. Some argued for systematic evaluation of and specific feedback on their patients' behaviour by parents or health care workers, in order to assess the effect of medication:

> *I need observations and detailed feedback. There's no point in continuing a treatment if it isn't effective. Systematic feedback is the required way of working. (GP #7)*

Others wanted a standard feedback sheet:

> *Then you can have a summary over a longer time perspective, rather than some random reports. But I don't know where to get these schemes. (GP #10)*

As schemes or more objective feedback forms were not often provided, the participants were forced to rely upon normative assessments provided by accompanying health workers or parents.

DISCUSSION

Summary of main findings

The results in this study highlight the complexity of providing GP services to people with ID and MBP. The GPs interviewed in this study were strategically selected and were expected to have above-average engagement and competence with this patient group. Evidence-based medicine requires a combination of clinical expertise, best available external evidence and individual patient needs and choices.[26] The competence of the participants in this study is generally experience-based on this topic and therefore characterised by individual opinions and ways of working. The participants described limited education on ID issues, and none could refer to any scientific article, book or report on this topic. Even though there has been a course directed to GPs on ID patients, with a subcategory on MBP, none of the participants had attended it. This study implies that GPs with more than usual level of experience and interest in patients with ID and MBP, mainly relies on experience based knowledge, and have limited knowledge of articles, guidelines, reports or books on this topic. The fact that challenges managing patients with ID and MBP nearly is taught in medical school and the only course available is an internet course may contribute to the understanding of limited evidence based knowledge among the participants. In addition, our results imply that this topic is rarely mentioned in scientific papers or on conferences and courses with GP participation.

Strengths and limitations of the study

The participants in this study were strategically selected, thereby representing a relatively homogenous group. This situation creates an obvious threat to external validity, and may limit the generalisation of our results. Nevertheless the interviewees revealed diverse opinions and descriptions of their managing of ID patients with MBP, thereby strengthening our impression

that this is an important research topic, albeit rarely investigated or highlighted in national or international settings. Everyone in our research group has read and analysed the transcripts and independently noted meaningful units. The group comprises researchers and clinicians from several areas, thereby limiting the threat of a subjective finding with idiosyncratic perspectives and limited objective value. Our findings can be transferred to clinical situations and can provide a good starting point for further research in the field.

Comparison with existing literature

There is no hard evidence for the necessity and efficacy of using psychotropic medication for treating MBP in people with ID.[27-30] The fact that none of the GPs interviewed could mention any scientific paper that addresses this problem supports the finding that this as an experience-based field, in which doctors rely on general competence valid for people without ID. This is a noteworthy result, especially given the assumption that 70% of psychotropic medication to this patient group is prescribed by the GP alone, without collaboration with a psychiatrist.[31,32] Furthermore the results are in line with findings from another qualitative study that addressed the educational needs of family physicians of people with ID, pointing out a need for modifications of their education.[20]

Implications for future research and clinical practice

The results demonstrate a major challenge to treatment of MBP in people with ID: None of the participants was sure how to treat these patients themselves, yet they were unsure where to refer their patients if they found the situation too complicated for primary health care treatment alone. They tended to distrust specialist health services. In some areas of the county, the GPs mentioned a local hospital psychiatrist, and other participants mentioned specific persons with whom they could collaborate. All in all, these statements serve to underline the importance of knowledge and information exchange between potential collaborative partners.

Our study shows that GPs' managing of patients with ID and MBP is primarily based upon experience-based knowledge – as told explicitly and as demonstrated through individual descriptions of managing and treatment. The GPs' opinions about working with ID patients is based on their own experience with this patient group, and with their general competence related to patients without ID. Attention should be focused on the ways in which medical training and post-graduate education can fill the competence gap, to ensure that this field becomes evidence-based rather than merely experience-based. As a start, the clinical guidelines from Canada mention some issues regarding people with ID and MBP[10], and should be marketed for GPs working with these patients.

Acknowledgements

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Competing interests

All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; and no other relationships or activities that could appear to have influenced the submitted work.

Ethics approval

The Norwegian regional committee for medical research approved this study.

Contributors

TF contributed to acquisition of data, transcription, analysing data, drafting and critical revision of the article and approval of the final version. ORH, LJD and LL contributed to the design of the study, analysing data, critical revision of the article and approval of the final version. KK participated in the interviews, analysing data, critical revision of the article and approval of the final version.

Data sharing

No additional data available.

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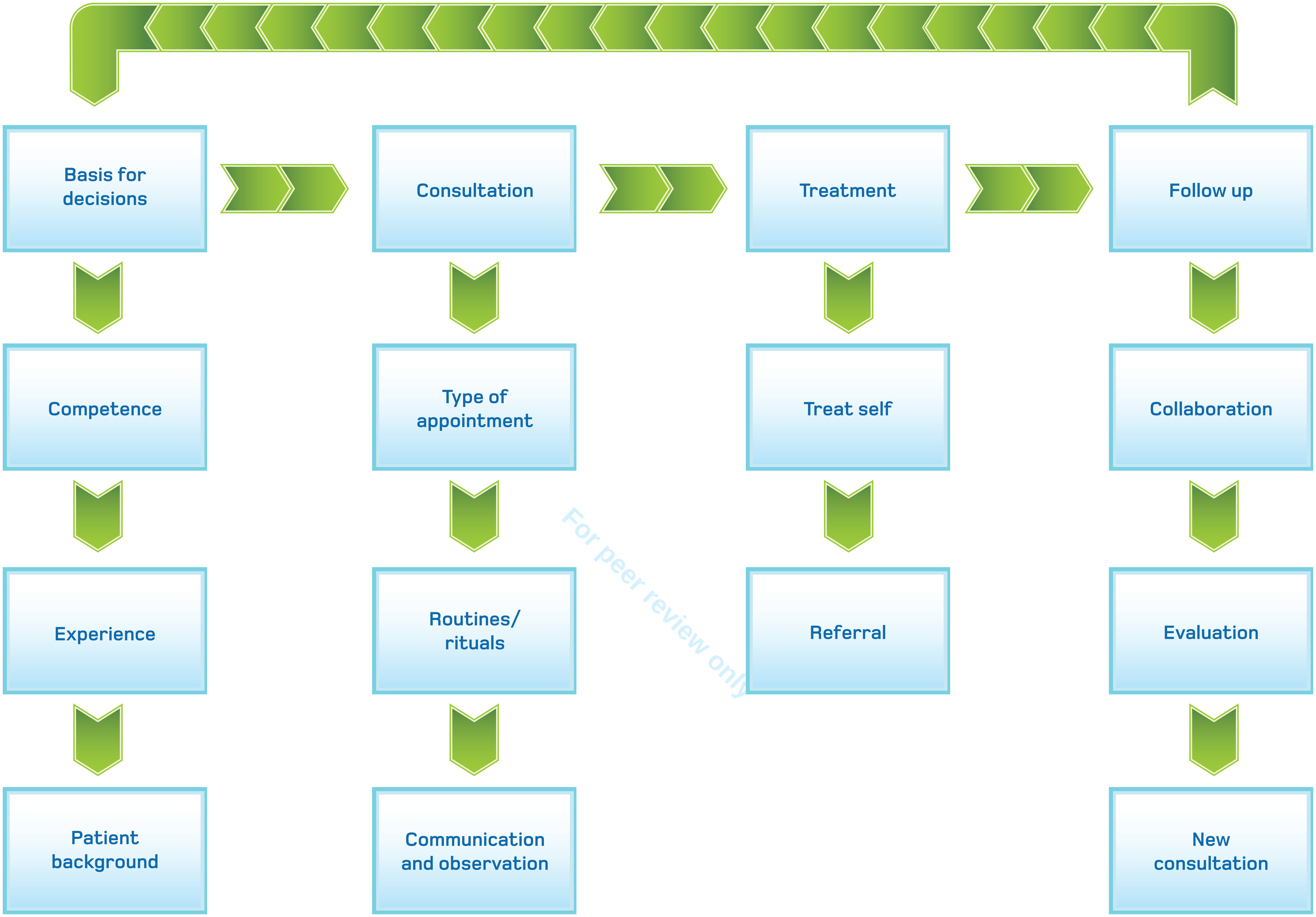
Basis for decisions
Consultation
Treatment
Follow up
Competence
Type of appointment
Treat self
Collaboration
Experience
Routines/ rituals
Referral
Evaluation
Patient background
Communication and observation
New consultation

Research check list - Fredheim et al. 2012

Domain 1: Research team and reflexivity

Personal characteristics

1. Interviewer/facilitator 1:	Terje Fredheim
2. Credentials:	MSc, Master of Learning in Complex Systems
3. Occupation:	PhD-student
4. Gender:	Male
5. Experience and training:	Educated in and have participated in earlier qualitative and quantitative research

1. Interviewer/facilitator 2:	Kari Kjønsberg
2. Credentials:	Reg. nurse, MMHC
3. Occupation:	Reg. nurse specialised in mental health care.
4. Gender:	Female
5. Experience and training:	educated in and have participated in different earlier qualitative health research studies.

Relationship with participants

6. Relationship established: There was no relationship prior to study commencement.
7. Participant knowledge of the interviewer: They were informed about researchers` professional background and interest in the project.
8. Interviewer characteristics: The interviewers` connection with specialised health care may be regarded as bias, but was considered as a minor problem. However the interviewers waited until the interview was over until they presented detailed information about prior experiences and information relevant for the topic.

Domain 2: Study design

Theoretical frame work

9. Methodological orientation and theory: The study relies on a phenomenological approach with content analysis and systematic text condensation as the main method in analysing data.

Participant selection

10. Sampling: Names of possible participants were given the interviewers from a senior psychiatrist retired after decades in habilitation services. Our research group regarded this psychiatrist to be the best source to help us find the sample of participants we were looking for. The interviewers then recruited strategically from this list to represent different gender, age, diagnosis and location (rural or city).
11. Method of approach: Participants were first contacted by letter. Two or three days after likely retrieval of the letter, possible participants were contacted by telephone. Information was given and request made, and appointment made with those who were positive.
12. Sample size: Ten participants were interviewed.
13. Non-participation: Five persons refused/hesitated to participate. No drop-outs. The reason for non-participation was not asked for.

Setting

14. Setting of data collection: All interviews were conducted in the participants` office or nearby meeting room.
15. Presence of non-participants: None.
16. Description of sample: Seven males and three females were interviewed. They represented various age and location (city/rural).

Data collection

17. Interview guide: A guide with themes and main questions was provided by the researchers and discussed with the supervisors. Also a checklist was used to get more information on topics that seemed important or topics not mentioned by the participant. No pilot was tested.
18. Repeat interviews: Repeated interviews were not used. Participants were encouraged to contact the interviewers if they wanted to add something and one of them made contact by telephone to give some more information.
19. Audio/visual recording: Audio recording was used to collect data.
20. Field notes: The two interviewers made field notes during the interviews, and immediately after each interview.
21. Duration: Interviews lasted 47 – 81 minutes.
22. Data saturation: Saturation and was discussed in the research group after the tenth interview had been conducted and was then regarded as satisfactory. We were open to the fact that new themes and important information could appear, but regarded the data material to contain breath and depth for the topic investigated.
23. Transcripts returned: Transcripts were not returned to participants for comment or corrections.

Domain 3. Analysis and findings

Data analysis

24. Number of data coders: All five in the research group read the complete transcript. One of the interviewers presented identified meaningful units and themes derivated from the material and they were discussed in the research group.
25. Description of the coding tree: The coding tree is illustrated with a figure of major and minor themes.
26. Derivation of themes: Themes emerged from the data.
27. Software: No additional software was used.
28. Participant checking: Participants were offered feedback on the findings. Five of them expressed a request for feedback when the material had been accepted for publication.

Reporting

29. Quotations presented: Participant quotations were used to illustrate findings. Quotations are not identified in this paper due to a small number of participants.
30. Data and findings consistent: The themes developed by the researcher(s) were logically consistent and reflective of the data.
31. Clarity of major themes: The major themes are described in the article, and reflect the research question.
32. Clarity of minor themes: Minor themes are described in the article, and reflect meaningful units. Diverse cases are described where necessary.

Cover letter Revision 1: Response to editor, and point-by-point response to the concerns of the reviewers.

Response to editor:

The manuscript has been edited, and all changes are highlighted in the manuscript using “track changes”. I have deleted all boxes in the right column to ease the reading of the manuscript. The research group found the peer review process very inspiring, and the reviewers’ comments have clarified the paper. Point-by-point response to the concerns of the reviewers has also been provided, and our answers are highlighted.

I do hope you find the changes satisfactory, and that the paper now better presents our findings, and is suitable for publication in BMJ Open.

Point-by-point response to the concerns of the reviewers:

First of all I would like to thank the reviewers for valuable comments on this paper. The comments have been important for this paper to clarify and present this research.

Reviewer: Elizabeth Barley, senior lecturer, Florence Nightingale School of Nursing and Midwifery, King's College London

This qualitative interview study investigates GPs' experience of people with intellectual disabilities and mental or behavioural problems.
A minor point: the authors used the term 'handling' people with intellectual disabilities, it would be preferable if this could be changed to a word with less negative connotations eg helping or managing or 'working with'.

Answer: Thank you for noticing us on the negative connotations of the term “handling”. It is changed to managing or helping.

Study aim: 'to explore the experiences, competences, attitudes and role of GPs......' this is clear, however the term 'competences' should be removed or changed as it is not possible to determine if the GPs are competent by interviewing them. It could be 'perceived competence', but you would have to make sure that you addressed this specifically in the interview, which at the moment it doesn't appear that you have. The same applies to the term role - perhaps you mean the GPs' 'perceived' role?

Answer: It is changed in accordance to the suggestions from the reviewer. As you say, it could be unclear to talk about competence and roles, since we did not explore that in a quantitative manner. Perceived role and competence is a better description, and this is what is discussed in the results section.

Methods: under participants you state that 'it was estimated that a smaple size of 7 to 10 ...would be required to achieve sufficient data and identify key themes' - on what is this estimate based, the reader needs to be convinced that this is the case in order to believe that all themes have been captured.

Answer: I have removed the part about estimation of sample size, since that is unclear and impossible to tell for sure. The researchers agreed that the transcripts from the interviews contained enough material to identify important themes. We can however not be sure that other important themes and issues could have been captured if even more participants had been interviewed.

setting - this section really describes your data collection process rather than the study setting.

Answer: It now contains a bit more about the setting, in addition to a description of the non existing relationship between the participants and the interviewers.

data collection - the two questions cited are very broad, it would be useful to see the topic guide, the 'additional checklist' that you refer to or a list of prompts used.

Answer: A list of additional prompts has been added, with a special focus on the keywords interesting for this paper.

You seem to be interested in whether an evidence based approach is taken, it would be useful to know what evidence based treatments/management strategies are available - you hint at this in places but for the non-specialist it would be useful to spell them out.

Answer: In the background section we have added a few sentences on this issue.

I can't see figure 1, so can't comment on this.

Answer: It is not clear why you couldn't see figure 1, but reviewer 2 has commented on this, and it is now changed due to this comments.

I would like to see more quotes which directly support the reported results. For instance, p8 'GPs described limited training....', 'GPs saw the advantage of being a faimily doctor'.....

Answer: Some quotes have been added to more directly illustrate and support the reported results.

P8 'none of them had knowledge of the NMA's internet course' - did you ask them directly? Also, what is this course?

Answer: The participants were asked directly, and some additional information on this course has been added.

Descriptions of some of the examples of patients described by the GPs may help the reader understand the issues better.

Answer: On page 8, in the beginning of the results section, we have added a case description to help the reader understand the complexity of these issues.

Discussion - I agree that your study highlights the complexity of providing services to these patients.
Your finding that GPs are uncertain/unhappy about the available specialist care is also important.

My main difficulty is around your conclusion that GPs' practice is experience rather than evidence based - this seems to be true, but what I can't tell from your paper is what evidence based treatment/policy/guidelines are available. You refer to things such as health checks and psychotropic medication use, but also state that there is a lack of standard guidelines. Is it the case that evidence based management strategies are available but that GPs ignore them/are unaware of them (in which case it would be good to understand why) or is it that the only option GPs have when dealing with these patients is to rely on their own experience? in which case it would be good to highlight what their specific difficulties are and how they could be addressed. From your 'comparison with exisiting literature' section it seems that the latter case is more likely, but this needs to be demonstrated consistently throughout the paper before it can be published. Otherwise this is an interesting paper.

Answer: Our results demonstrate that the GPs rely mainly on experience based knowledge. We have added some suggestions to an explanation of this finding in the “discussion section”. Some more specific information on the availability of literature and courses on this topic have been added. The question of evidence based practice is not a case of either/or, but the situation is complex, and it can be that ignorance, poor availability of courses/literature, little focus on this group of patients and trust in own experience together can explain the results better. We hope this is better demonstrated through the paper in the revised version.

Finally, you could make more of the fact that this is an under-researched area and the equity of care implications. You should be commended on starting to address this!

Answer: Thank you for pointing this out. This fact is addressed with more clarity a couple of places in the revised paper.

As far as I can tell there are no conflicts of interest. I can't see a number relating to the ethical approval.

Answer: The number relating to the ethical approval is 10-2008 SI.

Reviewer: Yona Lunsky, PhD
Centre for Addiction and Mental Health
Toronto, Canada

I have no competing interests in reviewing this manuscript.

This is a qualitative study and so some of the methodological questions do not apply but there is no N/A choice. I think their description of their coding process was clear.
In this study, participants are doctors, not patients but they are well described. That being said, it is important because this is an international audience to provide some information about the training of GPs as it relates to intellectual disabilities in addition to policy and services in the jurisdiction where this is written. The role of the GP and resources available to the GP vary by jurisdiction.

I would have liked to have sen further illustrative quotes to support some of the ideas put forth.

Answer: Several quotes have been added, as the same comment was put forth from reviewer one as well.

I thought this was a very interesting brief paper on a topic that does not receive significant research attention in mainstream medical journals. Using qualitative data, it provides a model to describe the process by which physicians work with this patient group (patients with ID and MBP) in their practice. The findings are important and speak to the need for further education and resources for GPs.

In general, I would like to see further illustrative quotes along with a richer discussion and contextualizing of findings. This would give greater assurance that the qualitative findings are accurate. It would be important to refer further to other qualitative studies on the experience of physicians serving this population. (ex. Wilkinson et al 2012. IDD, 50(3), 243-250). There are also qualitative studies of physicians working hospital settings that would be relevant. It might also be important to contextualize the experience of doctors with the experience of patients as part of the discussion. Several papers have been written on that. Some parts of the results do not seem particularly focused on issues unique to patients with ID and MBP. THis is important to comment on. Other issues are more specific to the MBP issues, particularly decisions around treatment and working with other professionals. If the theme of this paper is the unique challenges of MBP, then this should be made quite salient.

Answer: This is a comment that helps to clarify and increase the quality of the paper. Some further illustrative quotes have been added, and a case description has been added to help the reader understand the complexity of the issues in this paper. The findings from Wilkinson et al. have been described and added, both in the background section, and comparison with existing literature section. The paper has also been more focused on the special MBP issues, by adding specific information about education and papers, giving some description of typical challenges faced by the GPs, and discussing this unique challenge in the "discussion section".

I offer some specific comments below:
With regard to available tools and resources, there are guidelines and tools for GPs available and it could be helpful to make reference to them (e.g., Canadian Consensus Guidelines on Developmental Disabilities, Cdn Fam Physician, 57, 541-53).

Answer: These Canadian guidelines have been described shortly in the background section, and are also mentioned as a starting point to provide GPs with important peer reviewed literature on this topic.

I think the figure is a helpful guide to understand study results but there are some inconsistencies between the paper and figure that could be corrected.

The first box on left hand side: Before consultation could be changed to BASIS for Decisions, or Basis for treatment. The bottom box in that column could be renamed patient background because it is not about the patient's knowledge but about knowledge the GP has on the patient's background.

SEcond column: Type could be revised to read type of appointment. THe next two boxes, routines/rituals and communication/observation, get confused in the results section. It would be clearer if the text on page 10 begins with discussion of patient rituals and routines, and then a discussion on communication and obervation.

Answer: The figure is now corrected in response to these comments, and the results section better correspond to the figure when it comes to results in the subcategory “consultation”.

Treatment (pg 11)
the GP is actually making 1 decision with 2 choice options. COuld be rewritten as two choices the GP has when trying to solve the patient's...

Answer: This has been corrected in response to the comment.

Evaluating and Continuing Treatment (p13)
It was not clear to me whether the GPs felt like the meetings with non physicians ("Collaborators") were tailored in part to them ("structured towards their attendance") or whether they felt "left alone" in that process. Maybe the authors wanted to suggest that GPs felt including in discussions sometimes but others felt excluded. THis is an important finding so it needs to be clear. Is the sense of isolation because the GP does not feel like an expert or because the GP is excluded or feels excluded from these meetings?

Answer: This is important to clarify. Some additional information and quotes are added to better describe the situation the GPS are faced with, especially on p 14 and 15. The feeling of “being left alone” was mentioned when they were faced with medical questions, and the GPs had no collaborators to discuss these issues with in collaborative meetings.

Discussion
Summary of main findings: I did not think that this paragraph adequately summarized study findings.

Answer: The summary of main findings has been changed to better describe the findings as the revised paper now appears.

Comparison with existing literature:
I do not think thise section compares existing literature adequately. The only literature included is on efficacy of medications. There is a broader literature on physician preparedness and comfort. It would also be important to discuss training initiatives in the author's jurisdiction but also internationally to assist in helping GPs to feel more competent. Some key papers were not included here, including the work of Nick Lennox on physician attitudes and knowledge.

Answer: The comparison with existing literature have been extended. When it comes to training initiatives, some information about this issue have been written in the background section.

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Intellectual disability and mental health problems: a qualitative study of general practitioners' views

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Intellectual disability and mental health problems:

a qualitative study of general practitioners' views

Terje Fredheim[1,4]*, Ole R Haavet[4] Lars J Danbolt[1,3], Kari Kjønsberg[1], Lars Lien[1,2],

[1]Centre for Psychology of Religion, Innlandet Hospital Trust (SIHF), Hamar, Norway

[2] Faculty of public health, University College of Hedmark, Elverum, Norway

[3]Norwegian School of Theology, Oslo, Norway

[4]Department of General Practice, University of Oslo, Oslo, Norway

* Corresponding Author:

Terje Fredheim, Religionspsykologisk Senter, Postboks 68, N-2312 Ottestad

E-mail: terje.fredheim@sykehuset-innlandet.no

Phone: 0047 - 41219155

Article summary

Article focus

- The aim of this study was to investigate the general practitioners (GPs) experiences in managing people with intellectual disabilities and mental/behavioural problems (MBP) in order to identify factors related to high quality services, important areas for improvement and suggest fields for further exploration.

Key messages

- This study shows that GPs have different opinions on central subjects in providing high quality services to people with ID and MBP.
- Even GPs with an assumed high competence and engagement in this patient group, lack evidence based knowledge and base their actions on experience based practice.
- GPs are concerned about the competence in specialist departments when it comes to treatment of MBP in people with ID

Strenghts and limitations in this study

- Participants were of both genders, from several localities and had a broad range of patients with ID and MBP.
- As far as we know, this is the only study that has addressed GPs experiences with people with ID and MBP.
- Although data across participants were found sufficient, a small group of participants were interviewed.

Abstract

Objectives To investigate general practitioners' (GPs) experiences in managing patients with intellectual disabilities (ID) and mental and behavioural problems (MBP).

Design Qualitative study using in-depth interviews.

Setting General practice in Hedmark County, Norway.

Participants 10 GPs were qualitatively interviewed about their professional experience regarding patients with ID and MBP. Data were analysed by all authors using systematic text condensation.

Results The participants' knowledge was primarily experience based and collaboration with specialists seemed to be individual rather than systemic. The GPs provided divergent attitudes to referral, treatment, collaboration, regular health checks and home visits.

Conclusions GPs are in a position to provide evidence-based and individual treatment for both psychological and somatic problems among patients with ID. However, they do not appear to be making use of evidence-based treatment decisions. The GPs feel that they are left alone in decision making, and find it difficult to find trustworthy collaborative partners. The findings in this study provide useful information for further research in the field.

Introduction

People with intellectual disabilities (ID) are particularly vulnerable to health problems and experience difficulties in meeting their health care needs.[1-7] Two recent attempts provide a focus to this challenge: a consensus manifesto by the European Association of Intellectual Disability Medicine[8] and an independent inquiry on a request from the British Secretary of State for Health.[9] These reports share the goal of improving health care services for people with ID, but the extent to which their recommendations have been implemented remains dubious. Similarly, guidelines have been developed in other countries.[10-12] Courses are also available, for instance in Norway an internet course from the Norwegian Medical Association[14], and internationally a course from the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSID).[13] It is however not clear how widely such training programs for GPs are used.

A recent meta-analysis has shown that the prevalence of ID is approximately 1%.[15] Prevalence of mental health problems among people with ID vary in different studies from 14% to 60% and can be difficult to identify and diagnose.[16] There is considerable overlap between mental health problems and challenging behaviour[17,18]; these two complications are often inseparable, suggesting that there is little to gain from distinguishing between them when trying to identify implications for health workers. To detect and treat people with ID and mental and behaviour problems (MBP) is a test of the competence of the general practitioner (GP). Doctors specialising in general practice acquire knowledge about the early and general presentation of diseases, and early treatment and follow-up of chronic disease. GPs play a central role because of their familiarity with other primary health care services, as gate-keepers to specialist health care and in evaluating treatment and cooperate with the patient, family and other service providers.[19-22]

Each Norwegian GP has 5 to 10 patients with ID on their list. Some of these patients will have MBP, which potentially influences their physical health, including poor diet; erratic compliance with medication; and behaviour that can affect physical health, creating the need for close care and structure in health services.[23] A qualitative study has identified areas of discomfort when it comes to proper educational training for GPs, to meet the health needs of people with ID. [24] Results from another qualitative study with participants with ID showed that the participants wanted GPs with ability to listen interestingly, take the patient seriously and take the time to explain and demonstrate medical investigations. [7] GPs attitudes towards people with ID were investigated in a study. Although GPs held positive attitudes to managing ID patients they were not so willing to give more time in consultation.[25]

The importance of closely monitored care and high-quality health services to meet the challenge of inequality in health services for people with ID has provided the focus for several papers.[1,3,5,6,26] There are however few studies that have looked at the way GPs are working with patients with ID and MBP. The aim of our research was to explore the experiences, attitudes and perceived role and competence of GPs providing health services to patients with ID, with a special focus on patients with ID and MBP.

METHODS

A qualitative method

We opted for a qualitative approach, in order to obtain more detailed descriptions of the GPs' experiences serving patients with ID and MBP. In-depth interviews are suitable in inquiring about the GP's experiences, facilitating a deeper understanding of their opinions and attitudes.[27,28] We preferred open interviews to focus on each participant's descriptions and experiences, and bringing narratives into the method, by giving participants the opportunity to provide meaning to their responses.

Participants

Data were drawn from a total of 10 interviews with 10 participating GPs aged 41 to 64 (table 1). Participants were chosen following recommendations from an acknowledged senior psychiatrist with more than 30 years of experience with ID patients in collaboration with GPs in Hedmark County. There are 173 GPs in Hedmark, and the senior psychiatrist considered 25 of them to have more than the usual level of experience with ID patients and a relatively large number of ID patients on their list. A letter was sent to 15 of these GPs, purposefully selected with regard to geographical location and gender. 10 GPs were able to participate, 3 GPs refused to participate, and 2 GPs did not respond. Participation in this study was voluntary, and each participant signed an informed consent form, and was informed of their right to withdraw from the study at any time, without further explanation.

TABLE 1

Participant number	Age	Gender	Location	Total number of patients	Approximate number of ID patients	Reported number. of ID patients with psychiatric/ behavioural challenge
1	58	F	Rural	950	6	2
2	61	M	City	1200	3	2
3	60	M	Rural	800	14	4
4	64	M	City	2500	20	10
5	60	M	Rural	750	15	6
6	61	M	City	1000	5	?
7	60	M	City	1100	30	20
8	42	F	Rural	850	7	3
9	59	M	Rural	1000	12	6
10	41	F	Rural	1300	10	5

Participants' number, age, gender, location, total number of patients, approximately number of patients with ID, and reported number of ID-patients with mental or behavioural problems

Setting

All 10 interviews were conducted in the GPs' offices, located in Hedmark county, an agricultural county with small towns and a total population of approximately 190 000. The interviews lasted 41–81 minutes, with a mean of 57 minutes. Interviews were conducted from October to November 2011 and were audio recorded. All but one interview was conducted by two of the authors (TF and KK), and there were no former relationship between the participants and the interviewers. The interviews were planned, the participants were prepared on the topic and had allocated time for the interview. The interview consisted of open-ended questions based on an interview guide with two main questions:

1. What are your experiences with ID patients who have additional mental health problems and/or challenging behaviour?
2. What do you think is the GP's role for these patients?

The additional checklist was used to gather information that was otherwise missing or to provide greater depth or breadth to incomplete information. Follow-up questions were taken from a list of keywords; number of patients with ID on the GP's patient list, collaborative partners, regular health checks, specific training on the topic, perceived knowledge, knowledge of evidence based literature on the topic and attitude towards psychotropic treatment of people with ID.

Analysis

The interviewers made field notes with the participants' frequently used words, phrases and other statements requiring follow-up. Pauses, engagement, laughter and gestures were also noted, and the field notes were used in addition to the total transcripts. The 10 interviews generated approximately 119 pages of single-spaced text. Analysis of transcripts was conducted using systematic text condensation.[27,29,30] The first author read the transcripts several times to obtain a sense of the whole. The other authors independently read the transcripts and identified meaningful units, themes and subthemes, trying to capture the "essential expression". These findings were discussed among the authors.

RESULTS

During the interview, GPs described their experiences, consultations and collaboration with a variety of relatives and professionals. Case presentations included descriptions of ID patients with complex medical, psychiatric and behavioural challenges. GPs shared examples of what kind of challenges they were faced with managing these patients. It could be a patient with Down syndrome, psychiatric illness and difficult to control diabetes. Other patients could be aggressive both verbally and physically and not willing to participate in tests in a typical consultation at the doctor's office. Some of the patients lived alone with little community services, and were having a lifestyle with several potential harmful traits, like smoking, drinking alcohol or eating disorders, and limited cognitive resources to understand the consequences of their actions.

As a model of analysis, the process of a consultation emerged from the material as the best description of the GPs' experiences with this group of patients (figure 1). This model illustrates a GP's pathway through a consultation with four main categories: basis for decisions, consultation, treatment and follow-up.

Figure 1 approximately here

Basis for decisions

The main category, *basis for decisions,* epitomizes the GP's knowledge and experience in the context of the patient group and describes their medical education, experiences, courses and relevant post-graduate education on this topic. The GPs described limited training in patients with ID from their medical school or post-graduate courses. On direct question, none of the GPs' had knowledge of The Medical Associations internet-based course on the topic.

> *The Norwegian Medical Association arranges a lot of courses, but I have until today's date never seen a course on this topic. (GP #6)*

When the GPs' were directly asked on what basis they treated these patients there was no mention of articles, books or peer-reviewed journals on the topic:

> *I think… those medications that I am used to prescribing, and that I know are effective in any or another way, I will use them as a common guideline. (GP #1)*

> *I have common knowledge about patients and psychiatry. I have a large number of patients and I have years of experience. (GP #4)*

> *It might be revealing, but I use common sense and my own experiences. (GP #9)*

> *I haven't read any literature on this theme, but I have learned some in collaborating with Habilitation services. (GP #6)*

Knowledge of the patients' background and continuity in the relationship between patient and physician were seen as key issues in providing the best service. Furthermore these GPs saw the advantage of being a family doctor, improving the relationship to the patients allowing the GP to make a better job of evaluating the biological, psychological and social strengths of the patients. As one participant said:

> *The family will be a support system for the patient anyway, so l see this as a great advantage. (GP #6)*

> *A patient of me, his sister and sister's child are my patients. His sister has been here, lying on the bench pregnant. He knows this, and we talk a little about it. It seems to make him more comfortable and familiar with the situation when he knows I am helping more of his family as well. I can measure his blood pressure and do blood samples, some thing he was not able to do at his former GP. (GP #1)*

A key finding in this category is that most of the treatment is founded on experience-based knowledge. The material was rich in descriptions of patient histories, organisational system changes and historical events in the ID health care service, together with private memories from childhood or random meetings with people with intellectual disability. Because experiences are individual, there were many different stories, opinions and points of view.

> *Already in primary school I went to a school where people with ID were integrated. Having contact with people with ID has never been strange or unfamiliar for me. (GP #8)*

Consultation

The second main category, *consultation*, covers type of consultation, communication and individual routines or rituals by either the GP or the patient. First there are descriptions of various types of consultations which can occur in either the office or the patient's home: acute consultation, planned evaluations of treatment and prescriptions, and health checks. The GPs varied in their opinions about the benefits and possibilities of seeing the patient at home, as quotes from these two doctors illustrate:

> *Home visits are soon to become a closed chapter in general practice, but with these patients I find it necessary to do home visits. Then I can see with my own eyes how things appear at home (GP #5).*

> *They need to be observed and… it is not always easy for a GP to be able to observe. A GP should stay in the office and be available for patients (GP #4).*

Furthermore the GPs have different opinions about the benefits and possibilities of regular health checks for this patient group. Lack of standard guidelines opens the door for individual solutions and a variety of explanations. One participant highlighted this patient group as bad requesters of health care, requiring closer follow-up:

> *We may not be optimally good at this, but we try to do it once a year, and that is about were it ends. Some have a health problem that leads to more frequent consultations; in those cases a yearly health control is less important. But in general these are patients who don't tend to promote themselves. (GP #9)*

There were descriptions of patients who went through special routines and rituals in their GP's office. It seemed to be important for the relationship between the GP and the patient that these routines be followed; the patient tended to be calmer allowing the doctor to undertake the necessary investigations. As one participant said:

> *He is sitting here, takes a glass of water, sits down again and drinks some water. Sometimes I am able to check his blood pressure and do blood tests. He was not able to do that with his previous GP (GP #1).*

Communication and observation is another cluster of experiences in this category. Some of these patients are obviously anxious about a consultation, and all GPs said that their focus was on the patient, communicating directly with the ID patients, even though they were accompanied by others. If something could not be done because of unwillingness or restlessness, they did not push the patient, but booked another appointment in the near future.

Our participants argued that their patients' should be accompanied by someone who knows the patient, their medical history and the reason for the consultation. Yet patients with communication problems were sometimes accompanied to the doctor's office by health workers with limited knowledge of the patient. Because GPs must rely on information from accompanying persons, they would sometimes send the patient home with a new appointment. As one participant said:

> *It is essential that we have confidence in the information we are given. And that it is not exaggerated, hyped or trivialized, but is a sober description that it is possible for me as a GP to navigate towards (GP #7).*

Some participants were more likely to use systematic consultations and follow-up, especially if the patient had chronic somatic problems. Nevertheless, the somatic problem, rather than the ID and MBP constituted the main reason for systematic and frequent consultations.

Treatment

This third main category covers the choice the GP must make in trying to solve the patient's medical or mental health problem: to treat the patient or refer to a specialist. The participants expressed insecurity about how to treat and what to do with these patients. They described types and possibilities when they wanted to treat the patient themselves following these justifications: i) lack of confidence that a specialist would do the best job with these patients or ii) they believed the referral would be refused by the specialists' health services. This participant illustrates the lack of confidence in specialist services, and trust in own competence:

> *I have to call a random chief doctor at the local psychiatric institution, because that is what the habilitation services relies on… then I think I will do this better by myself. (GP #5)*

There were descriptions of all types of treatment, including check for somatic reasons for restlessness, behaviour modification, environmental actions and medical treatment. When the participants' referred these patients to specialist health services for their MBP, it was mainly for diagnostic work or medication queries. It was more common for the GPs to mention the name of a specialist rather than a specialist department.

> *If I wanted to refer a patient with these problems, NN was the person. (GP #3)*

> *NN2, a psychiatrist with long experience, is easy to turn to, because he provides good answers to my questions. (GP #8)*

Some of the GPs interviewed had created a private system to ensure systematic follow-up: prescribing medication over the short term and developing exclusive lists with patient data and consultation frequency.

Evaluation and continuing treatment

This fourth main category constitutes a cluster of descriptions covering collaboration, evaluation of treatment effects and routines for follow-up consultations. The participants reported their experiences with collaborative partners – particularly how they evaluated the effects of psychotropic medication.

A patient with ID and MBP nearly always involves one or more collaborative partners. Interdisciplinary meetings were described as useful if the GPs had the opportunity to participate. The GPs were not sure if they were invited to all meetings, but had the impression that their attendance and competence was wanted. There were descriptions of meetings with parents, community mental health workers, psychiatrists, psychologists and nursing home employees, but they differed in type, in the frequency of the GPs' attendance and in the priority they placed on them.

> *I try to attend every primary meeting with collaborative partners. (GP #9)*

> *I am not often called in to primary meetings. I am, in a few cases, where medical issues are central. (GP #7)*

The GPs that attended usually found meetings with collaborators useful, despite the fact that most of these meetings dealt with issues far from the GPs' areas of expertise. Some described meetings in which specific parts were structured towards their attendance, and this was considered to lower the barriers of GP attendance. Even though the GPs met a group of several collaborators facing the challenges of a patient, they felt alone in issues regarding medical questions for patients with ID and MBP. The feeling of being left alone was mentioned by several participants, but one participant was particularly clear about it:

> *I feel really alone on this topic with these patients. I don't really know what to do. (GP #10)*

The participants admit facing challenges in evaluating the effects of psychotropic medication. Some argued for systematic evaluation of and specific feedback on their patients' behaviour by parents or health care workers, in order to assess the effect of medication:

> *I need observations and detailed feedback. There's no point in continuing a treatment if it isn't effective. Systematic feedback is the required way of working. (GP #7)*

Others wanted a standard feedback sheet:

> *Then you can have a summary over a longer time perspective, rather than some random reports. But I don't know where to get these schemes. (GP #10)*

As schemes or more objective feedback forms were not often provided, the participants were forced to rely upon normative assessments provided by accompanying health workers or parents.

DISCUSSION

Summary of main findings

The results in this study highlight the complexity of providing GP services to people with ID and MBP. The GPs interviewed in this study were strategically selected and were expected to have above-average engagement and competence with this patient group. Evidence-based medicine requires a combination of clinical expertise, best available external evidence and individual patient needs and choices.[31] The competence of the participants in this study is generally experience-based on this topic and therefore characterised by individual opinions and ways of working. The participants described limited education on ID issues, and none could refer to any scientific article, book or report on this topic. Even though there has been a course directed to GPs on ID patients, with a subcategory on MBP, none of the participants had attended it. This study implies that GPs with more than usual level of experience and interest in patients with ID and MBP, rely on experience based knowledge, and have limited knowledge of articles, guidelines, reports or books on this topic. The fact that management of patients with ID and MBP rarely is taught in medical school and the only course available is an *internet course* may contribute to the understanding of limited evidence based knowledge among the participants. In addition, our results imply that this topic is rarely mentioned in scientific papers or on conferences and courses with GP participation.

Strengths and limitations of the study

The participants in this study were strategically selected, thereby representing a relatively homogenous group. This situation creates an obvious threat to external validity, and may limit the generalisation of our results. Nevertheless the interviewees revealed diverse opinions and descriptions of their managing of ID patients with MBP, thereby strengthening our impression that this is an important research topic, albeit rarely investigated or highlighted in national or international settings. Everyone in our research group has read and analysed the transcripts and independently noted meaningful units. The group comprises researchers and clinicians from several areas, thereby limiting the threat of a subjective finding with idiosyncratic perspectives and limited objective value. Our findings can be transferred to clinical situations and can provide a good starting point for further research in the field.

Comparison with existing literature

There is no hard evidence for the necessity and efficacy of using psychotropic medication for treating MBP in people with ID.[11,32-34] The fact that none of the GPs interviewed could mention any scientific paper that addresses this problem supports the finding that this as an experience-based field, in which doctors rely on general competence valid for people without ID. This is a noteworthy result, especially given the assumption that 70% of psychotropic medication to this patient group is prescribed by the GP alone, without collaboration with a psychiatrist.[35,36] Furthermore the results are in line with findings from another qualitative study that addressed the educational needs of family physicians of people with ID, pointing out a need for modifications of their education.[24] The GPs interviewed focused on communicating with the person with ID, giving them time to do their rituals, and the importance of building relations with the patients. People with ID have provided useful information in a qualitative study, focusing on the importance of practical issues like patience, demonstrations of medical investigations and communication with the patient, not the support person.[7] These attributes of a good patient doctor relation are also mentioned by patients with chronic problems without ID.[37]

Implications for future research and clinical practice

The results demonstrate a major challenge to treatment of MBP in people with ID: None of the participants was sure how to treat these patients themselves, yet they were unsure where to refer their patients if they found the situation too complicated for primary health care treatment alone. They tended to distrust specialist health services. In some areas of the county, the GPs mentioned a local hospital psychiatrist, and other participants mentioned specific persons with whom they could collaborate. All in all, these statements serve to underline the importance of knowledge and information exchange between potential collaborative partners.

Our study shows that GPs' managing of patients with ID and MBP is primarily based upon experience-based knowledge – as told explicitly and as demonstrated through individual descriptions of managing and treatment. The GPs' opinions about working with ID patients is based on their own experience with this patient group, and with their general competence related to patients without ID. Attention should be focused on the ways in which medical training and post-graduate education can fill the competence gap, to ensure that this field becomes evidence-based rather than merely experience-based. Guidelines for GP management of people with ID, with a subcategory focusing on MBP should be developed and disseminated in Norway.

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Competing interests

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Ethics approval

The Norwegian regional committee for medical research approved this study, ethical approval number 10-2008 SI.

Contributors

TF contributed to acquisition of data, transcription, analysing data, drafting and critical revision of the article and approval of the final version. ORH, LJD and LL contributed to the design of the study, analysing data, critical revision of the article and approval of the final

version. KK participated in the interviews, analysing data, critical revision of the article and approval of the final version.

Data sharing

No additional data available.

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Intellectual disability and mental health problems: a qualitative study of general practitioners' views

Terje Fredheim[1,4]*, Ole R Haavet[4] Lars J Danbolt[1,3], Kari Kjønsberg[1], Lars Lien[1,2],

[1]Centre for Psychology of Religion, Innlandet Hospital Trust (SIHF), Hamar, Norway

[2] Faculty of public health, University College of Hedmark, Elverum, Norway

[3]Norwegian School of Theology, Oslo, Norway

[4]Department of General Practice, University of Oslo, Oslo, Norway

* Corresponding Author:

Terje Fredheim, Religionspsykologisk Senter, Postboks 68, N-2312 Ottestad

E-mail: terje.fredheim@sykehuset-innlandet.no

Phone: 0047 - 41219155

Article summary

Article focus

- The aim of this study was to investigate the general practitioners (GPs) experiences in managing people with intellectual disabilities and mental/behavioural problems (MBP) in order to identify factors related to high quality services, important areas for improvement and suggest fields for further exploration.

Key messages

- This study shows that GPs have different opinions on central subjects in providing high quality services to people with ID and MBP.
- Even GPs with an assumed high competence and engagement in this patient group, lack evidence based knowledge and base their actions on experience based practice.
- GPs are concerned about the competence in specialist departments when it comes to treatment of MBP in people with ID

Strenghts and limitations in this study

- Participants were of both genders, from several localities and had a broad range of patients with ID and MBP.
- As far as we know, this is the only study that has addressed GPs experiences with people with ID and MBP.
- Although data across participants were found sufficient, a small group of participants were interviewed.

Abstract

Objectives To investigate general practitioners' (GPs) experiences in managing patients with intellectual disabilities (ID) and mental and behavioural problems (MBP).

Design Qualitative study using in-depth interviews.

Setting General practice in Hedmark County, Norway.

Participants 10 GPs were qualitatively interviewed about their professional experience regarding patients with ID and MBP. Data were analysed by all authors using systematic text condensation.

Results The participants' knowledge was primarily experience based and collaboration with specialists seemed to be individual rather than systemic. The GPs provided divergent attitudes to referral, treatment, collaboration, regular health checks and home visits.

Conclusions GPs are in a position to provide evidence-based and individual treatment for both psychological and somatic problems among patients with ID. However, they do not appear to be making use of evidence-based treatment decisions. The GPs feel that they are left alone in decision making, and find it difficult to find trustworthy collaborative partners. The findings in this study provide useful information for further research in the field.

Introduction

People with intellectual disabilities (ID) are particularly vulnerable to health problems and experience difficulties in meeting their health care needs.[1-7] Two recent attempts provide a focus to this challenge: a consensus manifesto by the European Association of Intellectual Disability Medicine[8] and an independent inquiry on a request from the British Secretary of State for Health.[9] These reports share the goal of improving health care services for people with ID, but the extent to which their recommendations have been implemented remains dubious. Similarly, guidelines have been developed in other countries.[10-12] Courses are also available, for instance in Norway an internet course from the Norwegian Medical Association[14], and internationally a course from the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSID).[13] It is however not clear how widely such training programs for GPs are used.

A recent meta-analysis has shown that the prevalence of ID is approximately 1%.[15] Prevalence of mental health problems among people with ID vary in different studies from 14% to 60% and can be difficult to identify and diagnose.[16] There is considerable overlap between mental health problems and challenging behaviour[17,18]; these two complications are often inseparable, suggesting that there is little to gain from distinguishing between them when trying to identify implications for health workers. To detect and treat people with ID and mental and behaviour problems (MBP) is a test of the competence of the general practitioner (GP). Doctors specialising in general practice acquire knowledge about the early and general presentation of diseases, and early treatment and follow-up of chronic disease. GPs play a central role because of their familiarity with other primary health care services, as gate-keepers to specialist health care and in evaluating treatment and cooperate with the patient, family and other service providers.[19-22]

Each Norwegian GP has 5 to 10 patients with ID on their list. Some of these patients will have MBP, which potentially influences their physical health, including poor diet; erratic compliance with medication; and behaviour that can affect physical health, creating the need for close care and structure in health services.[23] A qualitative study has identified areas of discomfort when it comes to proper educational training for GPs, to meet the health needs of people with ID. [24] Results from another qualitative study with participants with ID showed that the participants wanted GPs with ability to listen interestingly, take the patient seriously and take the time to explain and demonstrate medical investigations. [7] GPs attitudes towards people with ID were investigated in a study. Although GPs held positive attitudes to managing ID patients they were not so willing to give more time in consultation.[25]

The importance of closely monitored care and high-quality health services to meet the challenge of inequality in health services for people with ID has provided the focus for several papers.[1,3,5,6,26] There are however few studies that have looked at the way GPs are working with patients with ID and MBP. The aim of our research was to explore the experiences, attitudes and perceived role and competence of GPs providing health services to patients with ID, with a special focus on patients with ID and MBP.

METHODS

A qualitative method

We opted for a qualitative approach, in order to obtain more detailed descriptions of the GPs' experiences serving patients with ID and MBP. In-depth interviews are suitable in inquiring about the GP's experiences, facilitating a deeper understanding of their opinions and attitudes.[27,28] We preferred open interviews to focus on each participant's descriptions and experiences, and bringing narratives into the method, by giving participants the opportunity to provide meaning to their responses.

Participants

Data were drawn from a total of 10 interviews with 10 participating GPs aged 41 to 64 (table 1). Participants were chosen following recommendations from an acknowledged senior psychiatrist with more than 30 years of experience with ID patients in collaboration with GPs in Hedmark County. There are 173 GPs in Hedmark, and the senior psychiatrist considered 25 of them to have more than the usual level of experience with ID patients and a relatively large number of ID patients on their list. A letter was sent to 15 of these GPs, purposefully selected with regard to geographical location and gender. 10 GPs were able to participate, 3 GPs refused to participate, and 2 GPs did not respond. Participation in this study was voluntary, and each participant signed an informed consent form, and was informed of their right to withdraw from the study at any time, without further explanation.

TABLE 1

Participant number	Age	Gender	Location	Total number of patients	Approximate number of ID patients	Reported number. of ID patients with psychiatric/ behavioural challenge
1	58	F	Rural	950	6	2
2	61	M	City	1200	3	2
3	60	M	Rural	800	14	4
4	64	M	City	2500	20	10
5	60	M	Rural	750	15	6
6	61	M	City	1000	5	?
7	60	M	City	1100	30	20
8	42	F	Rural	850	7	3
9	59	M	Rural	1000	12	6
10	41	F	Rural	1300	10	5

Participants' number, age, gender, location, total number of patients, approximately number of patients with ID, and reported number of ID-patients with mental or behavioural problems

Setting

All 10 interviews were conducted in the GPs' offices, located in Hedmark county, an agricultural county with small towns and a total population of approximately 190 000. The interviews lasted 41–81 minutes, with a mean of 57 minutes. Interviews were conducted from October to November 2011 and were audio recorded. All but one interview was conducted by two of the authors (TF and KK), and there were no former relationship between the participants and the interviewers. The interviews were planned, the participants were prepared on the topic and had allocated time for the interview. The interview consisted of open-ended questions based on an interview guide with two main questions:

1. What are your experiences with ID patients who have additional mental health problems and/or challenging behaviour?
2. What do you think is the GP's role for these patients?

The additional checklist was used to gather information that was otherwise missing or to provide greater depth or breadth to incomplete information. Follow-up questions were taken from a list of keywords; number of patients with ID on the GP's patient list, collaborative partners, regular health checks, specific training on the topic, perceived knowledge, knowledge of evidence based literature on the topic and attitude towards psychotropic treatment of people with ID.

Analysis

The interviewers made field notes with the participants' frequently used words, phrases and other statements requiring follow-up. Pauses, engagement, laughter and gestures were also noted, and the field notes were used in addition to the total transcripts. The 10 interviews generated approximately 119 pages of single-spaced text. Analysis of transcripts was conducted using systematic text condensation.[27,29,30] The first author read the transcripts several times to obtain a sense of the whole. The other authors independently read the transcripts and identified meaningful units, themes and subthemes, trying to capture the "essential expression". These findings were discussed among the authors.

RESULTS

During the interview, GPs described their experiences, consultations and collaboration with a variety of relatives and professionals. Case presentations included descriptions of ID patients with complex medical, psychiatric and behavioural challenges. GPs shared examples of what kind of challenges they were faced with managing these patients. It could be a patient with Down syndrome, psychiatric illness and difficult to control diabetes. Other patients could be aggressive both verbally and physically and not willing to participate in tests in a typical consultation at the doctor's office. Some of the patients lived alone with little community services, and were having a lifestyle with several potential harmful traits, like smoking, drinking alcohol or eating disorders, and limited cognitive resources to understand the consequences of their actions.

As a model of analysis, the process of a consultation emerged from the material as the best description of the GPs' experiences with this group of patients (figure 1). This model illustrates a GP's pathway through a consultation with four main categories: basis for decisions, consultation, treatment and follow-up.

Figure 1 approximately here

Basis for decisions

The main category, *basis for decisions,* epitomizes the GP's knowledge and experience in the context of the patient group and describes their medical education, experiences, courses and relevant post-graduate education on this topic. The GPs described limited training in patients with ID from their medical school or post-graduate courses. On direct question, none of the GPs' had knowledge of The Medical Associations internet-based course on the topic.

> *The Norwegian Medical Association arranges a lot of courses, but I have until today's date never seen a course on this topic. (GP #6)*

When the GPs' were directly asked on what basis they treated these patients there was no mention of articles, books or peer-reviewed journals on the topic:

> *I think… those medications that I am used to prescribing, and that I know are effective in any or another way, I will use them as a common guideline. (GP #1)*

> *I have common knowledge about patients and psychiatry. I have a large number of patients and I have years of experience. (GP #4)*

> *It might be revealing, but I use common sense and my own experiences. (GP #9)*

> *I haven't read any literature on this theme, but I have learned some in collaborating with Habilitation services. (GP #6)*

Knowledge of the patients' background and continuity in the relationship between patient and physician were seen as key issues in providing the best service. Furthermore these GPs saw the advantage of being a family doctor, improving the relationship to the patients allowing the GP to make a better job of evaluating the biological, psychological and social strengths of the patients. As one participant said:

> *The family will be a support system for the patient anyway, so l see this as a great advantage. (GP #6)*

> *A patient of me, his sister and sister's child are my patients. His sister has been here, lying on the bench pregnant. He knows this, and we talk a little about it. It seems to make him more comfortable and familiar with the situation when he knows I am helping more of his family as well. I can measure his blood pressure and do blood samples, some thing he was not able to do at his former GP. (GP #1)*

A key finding in this category is that most of the treatment is founded on experience-based knowledge. The material was rich in descriptions of patient histories, organisational system changes and historical events in the ID health care service, together with private memories from childhood or random meetings with people with intellectual disability. Because experiences are individual, there were many different stories, opinions and points of view.

> *Already in primary school I went to a school where people with ID were integrated. Having contact with people with ID has never been strange or unfamiliar for me. (GP #8)*

Consultation

The second main category, *consultation*, covers type of consultation, communication and individual routines or rituals by either the GP or the patient. First there are descriptions of various types of consultations which can occur in either the office or the patient's home: acute consultation, planned evaluations of treatment and prescriptions, and health checks. The GPs varied in their opinions about the benefits and possibilities of seeing the patient at home, as quotes from these two doctors illustrate:

> *Home visits are soon to become a closed chapter in general practice, but with these patients I find it necessary to do home visits. Then I can see with my own eyes how things appear at home (GP #5).*

> *They need to be observed and… it is not always easy for a GP to be able to observe. A GP should stay in the office and be available for patients (GP #4).*

Furthermore the GPs have different opinions about the benefits and possibilities of regular health checks for this patient group. Lack of standard guidelines opens the door for individual solutions and a variety of explanations. One participant highlighted this patient group as bad requesters of health care, requiring closer follow-up:

> *We may not be optimally good at this, but we try to do it once a year, and that is about were it ends. Some have a health problem that leads to more frequent consultations; in those cases a yearly health control is less important. But in general these are patients who don't tend to promote themselves. (GP #9)*

There were descriptions of patients who went through special routines and rituals in their GP's office. It seemed to be important for the relationship between the GP and the patient that these routines be followed; the patient tended to be calmer allowing the doctor to undertake the necessary investigations. As one participant said:

> *He is sitting here, takes a glass of water, sits down again and drinks some water. Sometimes I am able to check his blood pressure and do blood tests. He was not able to do that with his previous GP (GP #1).*

Communication and observation is another cluster of experiences in this category. Some of these patients are obviously anxious about a consultation, and all GPs said that their focus was on the patient, communicating directly with the ID patients, even though they were accompanied by others. If something could not be done because of unwillingness or restlessness, they did not push the patient, but booked another appointment in the near future.

Our participants argued that their patients' should be accompanied by someone who knows the patient, their medical history and the reason for the consultation. Yet patients with communication problems were sometimes accompanied to the doctor's office by health workers with limited knowledge of the patient. Because GPs must rely on information from accompanying persons, they would sometimes send the patient home with a new appointment. As one participant said:

> *It is essential that we have confidence in the information we are given. And that it is not exaggerated, hyped or trivialized, but is a sober description that it is possible for me as a GP to navigate towards (GP #7).*

Some participants were more likely to use systematic consultations and follow-up, especially if the patient had chronic somatic problems. Nevertheless, the somatic problem, rather than the ID and MBP constituted the main reason for systematic and frequent consultations.

Treatment

This third main category covers the choice the GP must make in trying to solve the patient's medical or mental health problem: to treat the patient or refer to a specialist. The participants expressed insecurity about how to treat and what to do with these patients. They described types and possibilities when they wanted to treat the patient themselves following these justifications: i) lack of confidence that a specialist would do the best job with these patients or ii) they believed the referral would be refused by the specialists' health services. This participant illustrates the lack of confidence in specialist services, and trust in own competence:

> *I have to call a random chief doctor at the local psychiatric institution, because that is what the habilitation services relies on… then I think I will do this better by myself. (GP #5)*

There were descriptions of all types of treatment, including check for somatic reasons for restlessness, behaviour modification, environmental actions and medical treatment. When the participants' referred these patients to specialist health services for their MBP, it was mainly for diagnostic work or medication queries. It was more common for the GPs to mention the name of a specialist rather than a specialist department.

> *If I wanted to refer a patient with these problems, NN was the person. (GP #3)*

> *NN2, a psychiatrist with long experience, is easy to turn to, because he provides good answers to my questions. (GP #8)*

Some of the GPs interviewed had created a private system to ensure systematic follow-up: prescribing medication over the short term and developing exclusive lists with patient data and consultation frequency.

Evaluation and continuing treatment

This fourth main category constitutes a cluster of descriptions covering collaboration, evaluation of treatment effects and routines for follow-up consultations. The participants reported their experiences with collaborative partners – particularly how they evaluated the effects of psychotropic medication.

A patient with ID and MBP nearly always involves one or more collaborative partners. Interdisciplinary meetings were described as useful if the GPs had the opportunity to participate. The GPs were not sure if they were invited to all meetings, but had the impression that their attendance and competence was wanted. There were descriptions of meetings with parents, community mental health workers, psychiatrists, psychologists and nursing home employees, but they differed in type, in the frequency of the GPs' attendance and in the priority they placed on them.

> *I try to attend every primary meeting with collaborative partners. (GP #9)*

> *I am not often called in to primary meetings. I am, in a few cases, where medical issues are central. (GP #7)*

The GPs that attended usually found meetings with collaborators useful, despite the fact that most of these meetings dealt with issues far from the GPs' areas of expertise. Some described meetings in which specific parts were structured towards their attendance, and this was considered to lower the barriers of GP attendance. Even though the GPs met a group of several collaborators facing the challenges of a patient, they felt alone in issues regarding medical questions for patients with ID and MBP. The feeling of being left alone was mentioned by several participants, but one participant was particularly clear about it:

> *I feel really alone on this topic with these patients. I don't really know what to do. (GP #10)*

The participants admit facing challenges in evaluating the effects of psychotropic medication. Some argued for systematic evaluation of and specific feedback on their patients' behaviour by parents or health care workers, in order to assess the effect of medication:

> *I need observations and detailed feedback. There's no point in continuing a treatment if it isn't effective. Systematic feedback is the required way of working. (GP #7)*

Others wanted a standard feedback sheet:

> *Then you can have a summary over a longer time perspective, rather than some random reports. But I don't know where to get these schemes. (GP #10)*

As schemes or more objective feedback forms were not often provided, the participants were forced to rely upon normative assessments provided by accompanying health workers or parents.

DISCUSSION

Summary of main findings

The results in this study highlight the complexity of providing GP services to people with ID and MBP. The GPs interviewed in this study were strategically selected and were expected to have above-average engagement and competence with this patient group. Evidence-based medicine requires a combination of clinical expertise, best available external evidence and individual patient needs and choices.[31] The competence of the participants in this study is generally experience-based on this topic and therefore characterised by individual opinions and ways of working. The participants described limited education on ID issues, and none could refer to any scientific article, book or report on this topic. Even though there has been a course directed to GPs on ID patients, with a subcategory on MBP, none of the participants had attended it. This study implies that GPs with more than usual level of experience and interest in patients with ID and MBP, rely on experience based knowledge, and have limited knowledge of articles, guidelines, reports or books on this topic. The fact that management of patients with ID and MBP rarely is taught in medical school and the only course available is an *internet course* may contribute to the understanding of limited evidence based knowledge among the participants. In addition, our results imply that this topic is rarely mentioned in scientific papers or on conferences and courses with GP participation.

Strengths and limitations of the study

The participants in this study were strategically selected, thereby representing a relatively homogenous group. This situation creates an obvious threat to external validity, and may limit the generalisation of our results. Nevertheless the interviewees revealed diverse opinions and descriptions of their managing of ID patients with MBP, thereby strengthening our impression that this is an important research topic, albeit rarely investigated or highlighted in national or international settings. Everyone in our research group has read and analysed the transcripts and independently noted meaningful units. The group comprises researchers and clinicians from several areas, thereby limiting the threat of a subjective finding with idiosyncratic perspectives and limited objective value. Our findings can be transferred to clinical situations and can provide a good starting point for further research in the field.

Comparison with existing literature

There is no hard evidence for the necessity and efficacy of using psychotropic medication for treating MBP in people with ID.[11,32-34] The fact that none of the GPs interviewed could mention any scientific paper that addresses this problem supports the finding that this as an experience-based field, in which doctors rely on general competence valid for people without ID. This is a noteworthy result, especially given the assumption that 70% of psychotropic medication to this patient group is prescribed by the GP alone, without collaboration with a psychiatrist.[35,36] Furthermore the results are in line with findings from another qualitative study that addressed the educational needs of family physicians of people with ID, pointing out a need for modifications of their education.[24] The GPs interviewed focused on communicating with the person with ID, giving them time to do their rituals, and the importance of building relations with the patients. People with ID have provided useful information in a qualitative study, focusing on the importance of practical issues like patience, demonstrations of medical investigations and communication with the patient, not the support person.[7] These attributes of a good patient doctor relation are also mentioned by patients with chronic problems without ID.[37]

Implications for future research and clinical practice

The results demonstrate a major challenge to treatment of MBP in people with ID: None of the participants was sure how to treat these patients themselves, yet they were unsure where to refer their patients if they found the situation too complicated for primary health care treatment alone. They tended to distrust specialist health services. In some areas of the county, the GPs mentioned a local hospital psychiatrist, and other participants mentioned specific persons with whom they could collaborate. All in all, these statements serve to underline the importance of knowledge and information exchange between potential collaborative partners.

Our study shows that GPs' managing of patients with ID and MBP is primarily based upon experience-based knowledge – as told explicitly and as demonstrated through individual descriptions of managing and treatment. The GPs' opinions about working with ID patients is based on their own experience with this patient group, and with their general competence related to patients without ID. Attention should be focused on the ways in which medical training and post-graduate education can fill the competence gap, to ensure that this field becomes evidence-based rather than merely experience-based. Guidelines for GP management of people with ID, with a subcategory focusing on MBP should be developed and disseminated in Norway.

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Competing interests

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Ethics approval

The Norwegian regional committee for medical research approved this study, ethical approval number 10-2008 SI.

Contributors

TF contributed to acquisition of data, transcription, analysing data, drafting and critical revision of the article and approval of the final version. ORH, LJD and LL contributed to the design of the study, analysing data, critical revision of the article and approval of the final

version. KK participated in the interviews, analysing data, critical revision of the article and approval of the final version.

Data sharing

No additional data available.

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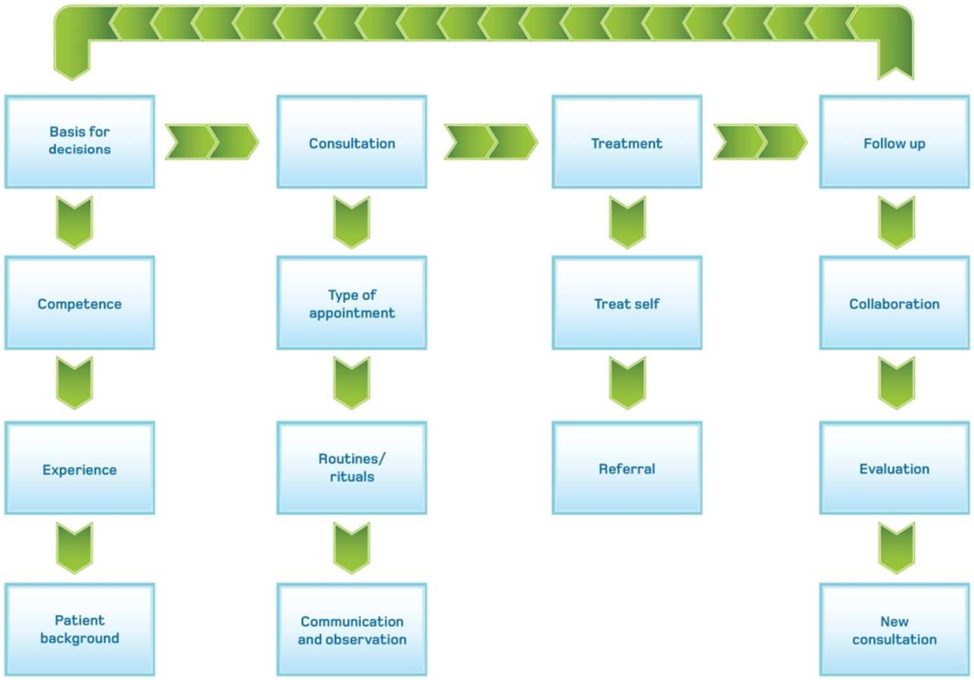

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Research check list - Fredheim et al. 2012

Domain 1: Research team and reflexivity

Personal characteristics

1. Interviewer/facilitator 1:	Terje Fredheim
2. Credentials:	MSc, Master of Learning in Complex Systems
3. Occupation:	PhD-student
4. Gender:	Male
5. Experience and training:	Educated in and have participated in earlier qualitative and quantitative research

1. Interviewer/facilitator 2:	Kari Kjønsberg
2. Credentials:	Reg. nurse, MMHC
3. Occupation:	Reg. nurse specialised in mental health care.
4. Gender:	Female
5. Experience and training:	educated in and have participated in different earlier qualitative health research studies.

Relationship with participants

6. Relationship established: There was no relationship prior to study commencement.
7. Participant knowledge of the interviewer: They were informed about researchers` professional background and interest in the project.
8. Interviewer characteristics: The interviewers` connection with specialised health care may be regarded as bias, but was considered as a minor problem. However the interviewers waited until the interview was over until they presented detailed information about prior experiences and information relevant for the topic.

Domain 2: Study design

Theoretical frame work

9. Methodological orientation and theory: The study relies on a phenomenological approach with content analysis and systematic text condensation as the main method in analysing data.

Participant selection

10. Sampling: Names of possible participants were given the interviewers from a senior psychiatrist retired after decades in habilitation services. Our research group regarded this psychiatrist to be the best source to help us find the sample of participants we were looking for. The interviewers then recruited strategically from this list to represent different gender, age, diagnosis and location (rural or city).
11. Method of approach: Participants were first contacted by letter. Two or three days after likely retrieval of the letter, possible participants were contacted by telephone. Information was given and request made, and appointment made with those who were positive.
12. Sample size: Ten participants were interviewed.
13. Non-participation: Five persons refused/hesitated to participate. No drop-outs. The reason for non-participation was not asked for.

Setting

14. Setting of data collection: All interviews were conducted in the participants` office or nearby meeting room.
15. Presence of non-participants: None.
16. Description of sample: Seven males and three females were interviewed. They represented various age and location (city/rural).

Data collection
17. Interview guide: A guide with themes and main questions was provided by the researchers and discussed with the supervisors. Also a checklist was used to get more information on topics that seemed important or topics not mentioned by the participant. No pilot was tested.
18. Repeat interviews: Repeated interviews were not used. Participants were encouraged to contact the interviewers if they wanted to add something and one of them made contact by telephone to give some more information.
19. Audio/visual recording: Audio recording was used to collect data.
20. Field notes: The two interviewers made field notes during the interviews, and immediately after each interview.
21. Duration: Interviews lasted 47 – 81 minutes.
22. Data saturation: Saturation and was discussed in the research group after the tenth interview had been conducted and was then regarded as satisfactory. We were open to the fact that new themes and important information could appear, but regarded the data material to contain breath and depth for the topic investigated.
23. Transcripts returned: Transcripts were not returned to participants for comment or corrections.

Domain 3. Analysis and findings

Data analysis
24. Number of data coders: All five in the research group read the complete transcript. One of the interviewers presented identified meaningful units and themes derivated from the material and they were discussed in the research group.
25. Description of the coding tree: The coding tree is illustrated with a figure of major and minor themes.
26. Derivation of themes: Themes emerged from the data.
27. Software: No additional software was used.
28. Participant checking: Participants were offered feedback on the findings. Five of them expressed a request for feedback when the material had been accepted for publication.

Reporting
29. Quotations presented: Participant quotations were used to illustrate findings. Quotations are not identified in this paper due to a small number of participants.
30. Data and findings consistent: The themes developed by the researcher(s) were logically consistent and reflective of the data.
31. Clarity of major themes: The major themes are described in the article, and reflect the research question.
32. Clarity of minor themes: Minor themes are described in the article, and reflect meaningful units. Diverse cases are described where necessary.