

## GPs' approaches to documenting stigmatising information:

a qualitative study

### Abstract

#### Background

Complete medical documentation is essential for continuity of care, but the competing need to protect patient confidentiality presents an ethical dilemma. This is particularly poignant for GPs because of their central role in facilitating continuity.

#### Aim

To examine how GPs manage medical documentation of stigmatising mental health (MH) and non-MH information.

#### Design and setting

A qualitative sub-study of a factorial experiment with GPs practising in Massachusetts, US.

#### Method

Semi-structured interviews ( $n = 128$ ) were audiorecorded and transcribed verbatim. Transcripts were coded and analysed for themes.

#### Results

GPs expressed difficulties with and inconsistent strategies for documenting stigmatising information. Without being asked directly about stigmatising information, 44 GPs (34%) expressed difficulties documenting it: whether to include clinically relevant but sensitive information, how to word it, and explaining to patients the importance of including it. Additionally, 75 GPs (59%) discussed strategies for managing documentation of stigmatising information. GPs reported four strategies that varied by type of information: to exclude stigmatising information to respect patient confidentiality (MH: 26%, non-MH: 43%); to include but restrict access to information (MH: 13%, non-MH: 25%); to include but neutralise information to minimise potential stigma (MH: 26%, non-MH: 29%); and to include stigmatising information given the potential impact on care (MH: 68%, non-MH: 32%).

#### Conclusion

Lack of consistency undermines the potential of medical documentation to efficiently facilitate continuous, coordinated health care because providers cannot be certain how to interpret what is or is not in the chart. A proactive consensus process within the field of primary care would provide much needed guidance for GPs and, ultimately, could enhance quality of care.

#### Keywords

continuity of care; documentation; ethics; primary health care; social stigma.

### INTRODUCTION

Comprehensive medical documentation is a vital element for providing high-quality, continuous health care. Yet, documenting sensitive or stigmatising information can compete with the goal of respecting patients' rights and maintaining confidentiality, leading to an ethical dilemma for providers.<sup>1–3</sup> Patients with potentially stigmatising conditions are often concerned that documented information could be used against them, do not want to share the information with family members, and regard the sharing of information between medical providers without prior consent as a breach of confidentiality.<sup>3–8</sup> Yet, lack of relevant information in the medical record may interfere with continuity of care and, as a result, reduce quality of care over time.<sup>9,10</sup>

This dilemma is particularly poignant in primary care given that GPs serve as the central point for a patient's care and therefore play an important role in facilitating continuity.<sup>11,12</sup> For patients with mental illness, GPs are often the first contact<sup>13</sup> and can play a pivotal role in managing their care.<sup>14</sup> Although there is much research about how GPs should manage mental health (MH) conditions<sup>15,16</sup> and ethically challenging situations in a manner that protects patient confidentiality,<sup>2,17</sup> there is little research on how GPs actually document stigmatising information.

Among MH clinicians, prior studies found that they often tailor their notes given the potential for patients accessing them,

are concerned about third parties using this information against their patients, and leave out sensitive and confidential information.<sup>18–20</sup> However, it is unclear whether GPs use similar strategies, whether the strategies differ by type of stigmatising information, or whether approaches are consistent among GPs. Given the central role of GPs in ensuring continuity of care, this study examined GP experiences with and strategies for documenting stigmatising MH and non-MH information. A qualitative approach was used to allow GPs to fully explain their perspectives in an open-ended manner.

### METHOD

#### Design

A qualitative sub-study was conducted as part of a randomised factorial experiment. Although the detail of the experimental design is not directly relevant to the qualitative results reported here, in brief, the experiment was designed to understand how the presence of stigmatising mental health comorbidities affect GP management of poorly controlled diabetes.

The sub-study entailed a semi-structured interview about what responders typically include and exclude from chart notes/medical records in their clinical practices. Qualitative interviews allowed for the emergence of unanticipated issues about GP approaches to chart narratives. Interviews were conducted in physician offices by interviewers trained in open-ended probing and lasted 10–15 minutes.

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### How this fits in

Despite the central role GPs play in continuity of care, little is known about how they manage the documentation of stigmatising information. This study reveals that a substantial proportion of physicians experience difficulties with documenting stigmatising information, and their strategies are inconsistent. Reaching a consensus within the field about an appropriate balance of documenting patient information and protecting confidentiality would provide guidance for clinicians and facilitate interpretation of what is and is not included in medical notes.

Responders took part in the qualitative interview after viewing a video vignette of a patient with diabetes and one of four comorbidities (schizophrenia with bizarre affect, schizophrenia with normal affect, depression, or eczema as control). Although patients with serious mental illness were part of the experimental design, GPs were not asked to comment on stigmatising information during the qualitative interview and the data for this analysis did not include comments about the vignette patient in particular. As a result, all data regarding documenting stigmatising information are responder-initiated.

### Participants

Participants were GPs practising in Massachusetts, US in 2010. Physicians were eligible to participate if they were internists or family practitioners with MD degrees (international physicians were included); had graduated from medical school during 1990–2006 or 1965–1989 (to stratify by clinical experience); and were currently working in primary care in Massachusetts more than half-time. GPs were recruited from a statewide list of physicians into four cells: sex (male or female) and two levels of experience (4–20 years or >21 years). Analysis was conducted with 128 GPs, evenly balanced by sex ( $n = 64$  male,  $n = 64$  female) and level of experience ( $n = 64$  with 4–20 years' experience,  $n = 64$  with  $\geq 21$  years' experience).

### Analytic approach

Interviews were recorded digitally and transcribed verbatim. Transcripts were imported into ATLAS.ti qualitative analysis software to facilitate data management and analysis.

A descriptive thematic analytical approach was used<sup>21</sup> and began with the initial coding

of the interviews.<sup>22</sup> A subset of transcripts were independently coded, identified, all coding disagreements resolved, and a codebook developed. These initial codes were applied to a different set of transcripts, compared, a consensus reached, and codes added and revised as needed. This process led to focused coding, the codes that were being used more often were elaborated.<sup>22</sup> This process was repeated for five batches of transcripts, after which a final code list was agreed and applied consistently. Following this, transcripts were coded in batches, discussed and issues resolved.

Following coding, the frequency of the most common codes was identified and compared by information type (MH or non-MH). Quotations for pertinent codes were closely read to develop themes, which were discussed. The general principles for enhancing analytic rigour were followed: transparency of method, maximisation of validity including attention to deviant cases, maximisation of reliability (including frequency counts of coded categories), constant comparison within the data set and within a case, and a reflexive approach to analysis.<sup>23</sup>

### RESULTS

Responders raised several types of patient information that they considered to be stigmatising: mental illness, substance abuse, drug dealing, sexual abuse, domestic violence, child abuse, human immunodeficiency virus status, multiple sexual partners, sexual preferences, sexually transmitted diseases (STDs) that may be stigmatising, extramarital affairs, social/family problems, abortion, and imprisonment. Results regarding managing these types of information emerged for two major categories and were consistent across the sex of physician and number of years of experience:

- difficulties in documenting stigmatising MH and non-MH information; and
- strategies for managing documentation of this information.

### Difficulties in documenting information

Without being specifically asked about stigmatising information, 44 GPs (34%) commented on difficulties in documenting it. Specific challenges were deciding whether to include clinically relevant but sensitive information, explaining to patients the importance of including relevant information, and finding appropriate wording for information they decided to include.

Typical examples of GPs expressing difficulty in deciding whether to include relevant information were:

*'There's some things that aren't included. There's some things that have to be included. And there's some things that you kind of just use your judgement and try your best to document, but it's tough.'* (ID: 103088)

*'It's really hard. I think I would say if a patient says "Don't put this in my chart", then maybe that shouldn't go in the chart and they're talking to you as a physician and it's very confidential interaction. The hard part is some of that information they may then tell you has a direct impact on their health.'* (ID: 206149)

GPs considered several criteria for deciding whether to include a piece of information: their judgement as to whether it would be dangerous to exclude the information, whether it was important for other practitioners to see the information, and how important it was to the patient, who could be forceful in asking that the information not be documented.

When interacting with patients, some GPs found it difficult to explain the importance of including relevant clinical information. For example, in the case of a patient with MH issues, a GP stated:

*'But sometimes people will ask you to not put things in there that are relevant, and it's hard to explain to them that's important to their medical care, and that people know. So that can be kind of an issue.'* (ID: 405242)

In another case of a patient with non-MH issues, a GP said:

*'Yeah, it's hard. And oftentimes I will tell them "If this is really, I think this has a direct impact on your health, I think I have a great memory and I might remember this but I don't, and I need, I need you to work with me so that I can take the best care of you possible, and that means that we really have to have everything out there and I can access it." And it's hard.'* (ID: 206149)

Even after deciding to include a piece of information, wording it appropriately was often a challenge. GPs were concerned that the way they worded potentially negative or embarrassing information may come across as being judgemental, which could offend the patient or stigmatise them if others read the medical record. As one GP stated:

*'I was just thinking, there's other things ... that one needs to be careful of. Let's say you don't believe the patient, or the patient is telling you some stories which you have a hard time to believe, or let's say you think they are drug-seeking, I think one needs to be careful when you put [that] down. You may describe the behaviour and make such a statement as "This behaviour is suggestive of drug-seeking behaviour" ... but in the real world ... when you have a limited amount of time, you may end up as putting just "Drug-seeking", and it might, you know, it might be counterproductive, it might be judgemental, and you know not the best way to do it.'* (ID: 305454)

In other cases, GPs had difficulty finding a way to word health-related information when patients asked that the context not be included in the record. For example:

*'Like I had someone a couple weeks ago, yeah, who was kind of involved in an affair situation and they were like "I don't want that in the chart", so I said "Okay", you know. It's a little hard, you know, because then when you're kind of like doing STD testing and things like that, it's like "Hmm, what diagnosis do I put?"'* (ID: 200200)

### Strategies for managing stigmatising MH and non-MH information

Although GPs were not asked about managing stigmatising information, more than half of the 128 GPs interviewed ( $n = 75$ , 59%) described strategies they used for managing sensitive MH and non-MH information (Table 1). Strategies were similar for documenting MH and non-MH information: to exclude stigmatising information to respect patient confidentiality, to include information but restrict access to it, to include but neutralise information to minimise potential stigma, and to include it given the potential impact on health care.

However, the proportion of GPs using each strategy differed somewhat by type of information.

**Excluding information to protect patient confidentiality.** Excluding information was more commonly used for non-MH than MH information. The reasons for exclusions were similar for both types of information: respecting patients' requests and potential non-medical consequences for patients.

Respect for the patient's wishes often led the GP to exclude information. One GP described a typical sentiment:

*I see a lot of mental illness and a lot of*

**Table 1. Strategies by type of stigmatising information (n = 75)**

Strategies <sup>a</sup>	Mental health information (n = 31), n(%)	Non-mental health information (n = 63), n(%)
Excluding information	8 (26)	27 (43)
Including but restricting access	4 (13)	16 (25)
Including but neutralising	8 (26)	18 (29)
Including information	21 (68)	20 (32)

<sup>a</sup>Responders could report using more than one strategy.

kind of depression kind of symptoms, and some people say "I don't want that in" ... I definitely try my best to respect patients' wishes, so it really kind of stems from there.' (ID: 103088)

In other cases, GPs decided not to include information because of the potential consequences for the patient if those outside the medical field accessed the information. As GPs explained:

*'For most of us, it would be if they didn't want to disclose an abuse history, sex abuse, or if he battered his wife and he was under investigation or his kids and they're DSS [Department of Social Services], and that's why he didn't feel well, he might not want that in the chart because there's actually legal issues. And he asked me not to include it in the chart, and I'm treating him for his diabetes and I'm not reporting him like as his kids' paediatrician, then I would respect his wishes.'* (ID: 104840)

*'There are people who will tell me not to put that down because they do not want to become uninsurable. So I will not put information that may interfere with their getting insurance, or life insurance or medical insurance.'* (ID: 400521)

Another example of excluding information concerned what to send to other providers, particularly specialists. As one GP described:

*'I suppose I would pick and choose what would be pertinent for [other providers] to know and, you know, most of the stuff is pertinent, especially from a psychiatric standpoint, but certainly not to a nutritionist. The nutritionist doesn't need to know their psychiatric history. I would just focus on his diabetic and hypertensive history, medications, recent lab results, that sort of thing. So I mean if he was going to see an endocrinologist because of uncontrolled diabetes that we weren't able to control with oral medications, and whether he needed to be put on insulin, you know, I think I would again address his most recent labs, his medications, and I don't necessarily think his psych history is necessary to be sent along to that specialist, so that probably wouldn't be included.'* (ID: 200387)

**Including information but restricting access.** A similar strategy that did not entail complete exclusion of information was to restrict access to certain pieces of information. GPs would limit some notes to

themselves by using 'sticky notes' or codes. Sticky notes allowed the GP to remember the issue without more general distribution. A GP explained:

*'So if I'm going to have something I have to put it in my desk, separate from their medical record, if a patient had a history of abuse, for example, that they didn't want a part of their medical record, or if they had other confidential issues that they didn't want a part of their medical record, I would keep it in my desk, separate from their medical record.'* (ID: 300113)

The information remained part of a 'secondary' medical record available only to the GP. In a few cases, the medical chart (paper or electronic) included confidential sticky note sections to facilitate this strategy. Other GPs used specific codes that only the GP understood:

*'Like if somebody's smoking dope and I'm afraid that by recording that in the chart it's going to say, you know, have some adverse effect on his career, and yet it's important for me to be aware of because it impacts on his weight or other, or lung problems, then I have little codes that I use to myself so that I'm going to know what it is, but it wouldn't necessarily be obvious to a casual reader.'* (ID: 301545)

This strategy of restricting access to information was more common for non-MH information.

**Including but neutralising stigmatising information.** For both MH and non-MH information, GPs used a strategy of neutralising sensitive information to avoid stigmatising patients or offending patients who accessed their records. For example:

*'I think I'm sort of being much more careful about the kind of words I'm using, because sometimes either the patient gets a copy of the note, or let's say the patient's record ends up at another doctor, and the doctor says "Oh, Dr Smith said ..." "He said that?" Or, yeah, I mean whatever way the patient may get the information, sometimes they take offence.'* (ID: 302559)

GPs using this strategy often kept their notes vague on sensitive issues so that other providers would not know details but the general issue was available in the record for follow-up if needed. As one GP stated:

*'I alluded to something that happened*

*without being specific and that essentially was the patient telling me that there's incest in the family ... So you allude to the fact that her trust was violated by someone close to her. That is vague enough that you don't really know what's going on unless you know the patient, and that's on purpose, because the patient doesn't want that to be known by anybody, for confidentiality reasons. So in a way I included a veiled reference to this and that can be explained if the patient chooses to explain it to the doctor. I know what it means and we leave it at that.'* (ID: 107721)

*Including stigmatising information to facilitate continuity of care.*

Including stigmatising information was most common for MH information, yet almost one-third of GPs who addressed how they manage sensitive non-MH information also included it in the medical record. For MH information, GPs referred to the need for providers to be aware of comorbidities. As a GP explained:

*'I think most of the times I do end up recording it in my note when I encounter patients with these types of issues. Because, I think, overall, you know, this is very important ... especially patients with diabetes, you know, there's like a very high percentage of depressions, comorbidities ...'* (ID: 110057)

For non-MH information, GPs who included stigmatising information felt it was important for them to remember this information in order to manage the patient effectively, even if the patient requested that it be excluded. In a GP's words:

*'I think anything can be part of the medical record, as far as I'm concerned. Even people who have told me "This is strictly confidential, I don't want anyone to know", they often tell me that they're a lesbian or they're sexually abused by someone. I always make a note of it, though, because otherwise I won't remember it so I won't be able to take care of that problem.'* (ID: 201050)

A few GPs who included all information explained that medical records were protected by privacy laws that prevented stigmatising information from being released:

*'But because the chart note is protected by HIPAA [Health Insurance Portability and Accountability Act], we really do need to put*

*down information, even if it's confidential, like sexual history.'* (ID: 203357)

## DISCUSSION

### Summary

This qualitative study revealed that GPs struggle with the ethical dilemma presented by the competing goals of, on the one hand, supporting continuity of care by documenting clinically relevant yet stigmatising information and, on the other hand, protecting patient privacy. Without being asked directly about stigmatising information, GPs raised three difficulties in documenting it: deciding whether to include it, explaining the need to include clinically relevant information to patients, and wording sensitive information appropriately. GP strategies for managing stigmatising information spanned the full continuum, from exclusion to inclusion. Some GPs excluded sensitive information to protect patient confidentiality, others masked it by restricting access or neutralising language, and still others included it given the potential effect on health care. Furthermore, these strategies were used at different rates for MH or non-MH information, and the intended audience affected what some GPs documented.

This study reveals that, in practice, GPs as a group are inconsistent about documentation of stigmatising information, suggesting a lack of consensus in the field. Inconsistent documentation among GPs may serve the individual needs of physicians and patients; however, without an agreed approach inconsistency among GPs can undermine continuity of care. Providers reading a medical record cannot be certain how to interpret what is or is not included. Is the information in the record masked in some way? Does the record include all the clinically relevant information, or have some pieces been excluded by another provider? Inconsistent documentation may also affect research using medical record data.<sup>9</sup>

### Strengths and limitations

The notable strengths of this analysis are the robust sample size for a qualitative study and the balanced sample of physicians, which ensured that the full range of GPs by sex and years of experience was represented. Limitations include generalisability, as the proportion of responders by sex and years of experience does not correspond directly to the population of GPs, and all responders were practising in one state in the US. Additionally, since all data were



responder-initiated, the rates of GPs' difficulties and strategies are likely to be under-reported. A larger survey asking about the themes identified here would provide more generalisable data and could identify factors that affect those results in certain subgroups (for example, practice culture).

### Comparison with existing literature

With the notable exception of including stigmatising information, the strategies that GPs in this sample used are similar to those of mental health clinicians. For example, in a survey of psychiatrists, 41% reported leaving out medical information, using generic wording, tailoring notes in case patients access them, and masking details or using 'shadow charts' to restrict access by non-MH providers.<sup>18-20,24</sup> While this prior research confirms the results about types of strategies found in the current study, the central role of GPs for coordination and continuity of care complicates any conclusion that strategies of masking or excluding information are optimal for a primary care setting.

Conflicting recommendations from existing literature have not resolved this dilemma for GPs. Recommendations to GPs on how to respond to confidentiality issues include the need to be aware of limits to confidentiality (for example, mandatory reporting laws, or third-party payer requirements) because patients may be unaware of these requirements and informing them can paradoxically lead to trust from patients.<sup>24</sup> Other recommendations focus on communication, such as ascertaining early on a patient's wishes regarding confidentiality and ongoing communication about privacy concerns for conditions such as alcohol abuse, depression, or other psychiatric disorders. Yet, many GPs in this study felt strongly about maintaining respect for their patients' confidentiality

concerns, which reflected another current view that protecting a patient's privacy is needed for achieving quality health care, particularly when caring for patients with stigmatising illness.<sup>17,25</sup>

The notable inconsistency among GPs in documenting stigmatising information suggests the need for a consensus process in the field of primary care to reach agreement on accepted practices for managing stigmatising information while still maintaining patient privacy and trust. Potential strategies include the four identified by this study, as well as alternatives recommended in the literature, such as making notations in the record about pieces of information not being documented.<sup>24</sup> This process should consider different audiences for patient information, potential legal exposure to physicians from negative clinical outcomes from excluded information, and the optimal balance of general guidelines and individual physician discretion. If the consensus is that some or all stigmatising information should be documented, the difficulty that GPs in this study expressed in finding appropriate words and explaining inclusion to patients suggests that GPs could benefit from better models.

### Implications for practice

This qualitative study identified GPs' difficulties with and inconsistent strategies for managing documentation of stigmatising MH and non-MH information. Without an agreed approach, inconsistency among GPs can undermine the potential for medical documentation to facilitate continuous, coordinated care efficiently because other providers cannot be certain how to interpret what is and is not in a patient's medical record. A proactive consensus process within the field of primary care would provide needed guidance for GPs and, ultimately, could enhance quality of care.

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### Ethical approval

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### Provenance

Freely submitted; externally peer reviewed.

### Competing interests

The authors have declared no competing interests.

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