

Discovering the research priorities of people with diabetes in a multicultural community: a focus group study

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ABSTRACT

Background

Usually experts decide on which research is worthwhile, yet it is government policy to involve service users in research. There has been a lack of published research about involving patients from minority ethnic groups and people from deprived areas in setting research agendas. In this study we wanted to hear the voices of patients that are not often heard.

Aim

To find out the research priorities of people with diabetes from an inner city community and compare these with current expert-led research priorities in diabetes.

Design of study

A qualitative study using a participatory approach with consumer groups.

Setting

Primary care within inner city Nottingham, UK.

Method

Thirty-nine adult patients with diabetes with varying ethnic backgrounds recruited from three general practices. Six focus groups carried out in participants' preferred language, analysed using the constant comparative method.

Results

Nine main themes equating to research priorities were identified. Within these themes, information and awareness, service delivery and primary prevention of diabetes emerged as the main factors. There were no science-based topics and there was more emphasis on culturally influenced research questions, which differed from recent Department of Health priorities. There were several themes about service delivery, patient self-management and screening and prevention of diabetes that overlapped.

Conclusions

There is some divergence between expert-led and patient-led agendas in research about diabetes. Patient perspectives have a significant influence on research priorities, and there are likely to be several different patient perspectives.

Keywords

diabetes mellitus; focus groups; multicultural; primary care; research priorities.

INTRODUCTION

Diabetes is one of the most common chronic illnesses in the UK¹ and is one of the government's seven lead research areas, forming part of the UK Clinical Research Networks from October 2004. Nearly £20 million of public money² was given in research funding during the year 2002–2003.

Traditionally, experts decide on which research is worthwhile and where research priorities lie. The Department of Health and the Medical Research Council Research Advisory Committee set up a review published in October 2002³ that set out the current and future research priorities on diabetes. This was intended to support the National Service Framework (NSF) for Diabetes⁴ and is likely to be used as a template for commissioning research over the next few years. Diabetes UK assisted in the review process, otherwise little opportunity was given to hear patients' views in this document.

It is NHS policy to involve service users in research.⁵ Involving users of health services may make research more focused on the research questions that will most closely impact on peoples' lives.⁶ It is still not known what factors are associated with successful public involvement in health research or how and in what way public involvement influences health research.⁷

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Submitted: 28 February 2005; Editor's response: 10 June 2005; final acceptance: 1 July 2005.

©British Journal of General Practice 2006; 56: 206–213.

There has been a lack of published research about involving patients from minority ethnic groups from deprived areas in setting research agendas. We aimed to find out the important aspects of the lives of some people with diabetes from a deprived inner city area, including people from minority ethnic groups. We wanted to define and prioritise research themes from these groups and compare and contrast these themes with the Research Advisory Committee research priorities.

METHOD

Participatory approach

Representatives of people with diabetes from inner city Nottingham, UK were invited to discuss possible collaborative research opportunities about diabetes. This included an Asian link worker, an African–Caribbean representative of Self-Help Nottingham, a representative of Diabetes UK, and several health professionals with an interest in diabetes working in primary care. This group decided that this study should concentrate on finding out what people with diabetes from inner city Nottingham considered to be the most important research for them.

Written methods of data collection such as a community survey would have been difficult to carry out, because of the known high illiteracy rate locally in both the English and Asian languages. As this was a cross-cultural study, and it was considered important to allow individuals to interact and ‘spark’ ideas from each other, focus groups were chosen as the best method to collect data.⁸

A multicultural, multidisciplinary research team of seven was formed to carry the research further. Two members could speak and translate Mirpuri Punjabi and one was at ease with patois. All members of the team were experienced facilitators and were involved in further developing the protocol of the study, including a topic guide that would be suitable for use with culturally diverse focus groups.⁹ All members undertook common training for focus group moderation and data analysis.

Two participants from the focus groups who expressed an interest in further involvement joined the research team to help analyse the data.

Recruitment and moderation

We held six focus groups. One consisted of Asian women, one Asian men, one African–Caribbean men and women, one completely mixed culture and sex, and one white mixed sex. These were selected on the basis that the focus groups should capture a full range of views on the topic¹⁰ and allow cultural and linguistic freedom of expression. The mixed culture and sex group provided an opportunity for those

How this fits in

Involving patients from a multicultural and deprived community gives a new perspective on diabetes research priorities and allows additional culturally-orientated research questions to be formulated. Participatory research identifies a research agenda that has both commonality and differences with those agendas derived from more formal expert-led approaches. Government priority to focus on long-term scientific research is at odds with public priority for research on non-scientifically based research that effects their daily lives. This study questions the best way to access users’ voices: do we need lots of perspectives?

preferring to attend groups not defined by sex, culture or language. A second white mixed sex group was held because the first contained only three participants.

Two GPs and one specialist diabetic nurse from the research team recruited patients from their lists by letter or telephone call. The eligibility criteria for invitation were a diagnosis of type 1 or type 2 diabetes and being aged 18 years or over. Any research team member who recruited participants to a particular focus group was not then involved in the running of that group. Present in each focus group were a moderator (able to speak the appropriate language), an assistant moderator to make notes and summarise (appropriate language required), and an observer to note group dynamics and help with whole group needs. Focus groups were held in local community centres or doctor’s surgeries. Informed written consent was gained from all participants at the start of each focus group.

Data collection and piloting

The interview topic guide was piloted with the first group of Asian women. No alterations were considered necessary to the topic guide and so these data were included in the analysis.¹⁰ The interview topic guide, used in all the groups, is outlined in Box 1. All the focus group discussions were tape recorded in their entirety. Each focus group lasted 60–90 minutes.

Participants were asked to consider important areas in their life and how these would influence research they would like to see carried out in diabetes. The process of prioritisation was sensitive to the high level of illiteracy and the cultural needs of the different focus groups. Participants’ discussions were summarised on a flip chart, which was then read out. The participants then discussed which topics they considered to be the most important issues for research. Although we asked participants to think about order of priority, this was not a consensus seeking exercise. In the Asian mens’ group the prioritisation process was entirely verbal as the group preferred to do it this way.

Box 1. Focus group topic guide.

Stage 1. Determining the issues

- ▶ As diabetics, what could be done to improve your everyday life?
Prompts
By family; by yourself; at work; by others (friends, neighbours, the media, 'heard about'); by the health service.
- ▶ What specific improvements would you like to see others make for diabetics that are connected with food and drink?
Prompts
Ask about weddings, lunch clubs, and festivals. Ask specifically about Ramadan.
- ▶ What specific improvements would you like to see others make for diabetics that are connected with treatment?
Prompts
Could use the word medicines and then broaden out to include the wider scope of medicine and include alternative/complementary medicine.
- ▶ What specific improvements would you like to see others make for diabetics that are connected with information?
Prompts
May need to be more specific, for example advice from doctors/nurses etc, leaflets, labelling etc
- ▶ Any other important areas outside these broad headings raised in stage 1.
- ▶ You have come up with lots of detailed improvements, are there any of them [look at flip chart/assistant moderator read out] that you can see or suggest what action needs to be taken to make them actually happen.
Prompts
Knowledge; science and technology; inventions; services.

Stage 2. Prioritisation

This leads to research ideas, written on a board and spoken out by assistant moderator

- ▶ Prioritisation exercise

Analysis

All tapes in the English language were transcribed verbatim. In the African–Caribbean group the transcript had to be re-examined by the group's moderator to interpret some of the patois language. Each focus group was analysed and coded by a pair, one of whom had been present at the focus group and one who had not. This was possible for all but the Asian language groups where analysis took place alongside translation by the researchers that moderated those groups. In this way the benefits of using researchers aware of the cultural values of the target group were combined with a similarly culturally sensitive approach to translation to improve the validity of the analysis.¹¹

The analysis process involved coding each focus group transcript individually. Consistency and fullness of coding was then examined before putting the data into categories and themes. Categories and themes from all the focus groups were collated and re-examined, looking for common categories across groups and categories that were unique to some groups. Murphy *et al*¹² have described this as the constant comparative method.

In the final stage of analysis, the research team and two of the focus group participants discussed

the preliminary findings and developed these into broad research themes and research questions. The areas of importance to the participants, how these translated to potential research ideas, and how these were prioritised were directly views expressed by participants in the focus groups. The thematic presentation of the research priorities and the refined research questions set out in Table 1 were interpretations of the findings by the research team but guided by the two participant representatives involved in the final stage of the analysis.

RESULTS

Characteristics of the focus group participants are shown in Table 2.

There were nine main themes of important aspects of peoples' lives identified by the focus groups. These themes are described below, using selected quotations from the focus groups to illustrate the most important issues.

Improving information

Improving the quality of delivery of information about diabetes in a clear and consistent way was seen as the most important issue. Every focus group discussed this at some length and emphasised its importance. The Asian and African–Caribbean groups wanted information about diabetes to be culturally appropriate:

'Most important, information to patients.' (Mixed group.)

'The information more than anything, proper information.' (Larger white group.)

'[Consistency of information is] very lacking I've found.' (Mixed group.)

'But what you've got to do is know which one is which, all those ideas and all that information, which is right for you?' (Mixed group.)

'I think they should tell you in a way you can understand.' (Asian female group.)

'Its difficult when you don't know much about your condition.' (Asian female group.)

'A lot of things that is written down is ignored. When the doctors speak to you first ... I think that information would be more noted.' (African–Caribbean group.)

'... and what we need now, and I don't think it will come, it will be the same case like sickle cell, it takes years before people appreciate how

Table 1. A Summary of the findings from the focus groups.

| Important aspects of the lives of people with diabetes, identified from the focus groups | Research themes developed from the important aspects |
|--|--|
| Improving information | What are the best ways of delivering information about diabetes to certain communities? <ul style="list-style-type: none"> • Quality of information is important • Cultural influences are important |
| Lack of public awareness | What is the extent of knowledge and understanding of diabetes in the general population? Does improving certain groups' knowledge help improve the outcomes of people with diabetes? |
| Improving information about food | How can information about food and diet best be delivered to people with diabetes? <ul style="list-style-type: none"> • Can food-labelling scales be used to help diabetic people understand sugar content of foodstuffs? • Can the food industry and the media help provide better information? • What is the level of awareness of appropriate diet and foods in Asian people with diabetes? What factors influence the application of knowledge about food and diet into improving health outcomes for diabetic people? <ul style="list-style-type: none"> • This may be culturally influenced and could be looked at in different groups of diabetic people |
| One-to-one support | Investigating the role of 'important others' in the health education of people with diabetes |
| Health services | How can services best support people with diabetes? <ul style="list-style-type: none"> • What is the role of specialist clinics in diabetes in primary care? • What factors in health professionals most help people with diabetes to manage their care? • What barriers are there in accessing care for diabetic people? • How culturally aware are health professionals working with diabetic people? |
| Prevention and screening | How best can the messages of prevention of diabetes be delivered? <ul style="list-style-type: none"> • Is there a role for mentors (role models, sports personalities etc) in schools to teach about diabetes? • Can public information about diabetes help to support people with diabetes? • How can friends and family of people with diabetes best be helped to support them? • Screening checks for people at risk for diabetes in the community (schools, mosques, churches etc). Evaluating their effectiveness. What is the understanding of risk in people with diabetes? <ul style="list-style-type: none"> • What is the understanding of risk in family members? • Using risk factor calculations to help people consider the risk of diabetes in their family members |
| Difficulties of comorbidity | How does comorbidity influence the self-management of diabetes? |
| Value of exercise | How can exercise be incorporated into the management of people with diabetes? How is the value of exercise best delivered to people with diabetes? |
| Self-management | What factors influence the self-management of diabetes in the Asian community? What are the perceptions of people with diabetes about their condition and how does it influence their self-management? |

dangerous it was ... it [diabetes] is bigger than anything.' (African-Caribbean group.)

think that you are a danger but you're not.' (Larger white group.)

Lack of public awareness

The next most important theme identified was the poor understanding that the general population have about diabetes and its consequences. Participants discussed the low media profile, the poor understanding by employers and little consideration for the needs of people with diabetes in pubs and cafes:

'I think in other people's psyche, I'm not saying we're aliens, but we're definitely the last people to be thought of.' (Mixed group.)

'Other people don't know the side effects you could get.' (Mixed group.)

'... some firms are frightened of diabetes, they

'... the management don't even ask you how you are ... it needs profiling a lot more.' (Small white group.)

'If you go into a diabetic coma while you're out and about how many of the public know if you've got diabetes or not?' (Larger white group.)

'Put it on the media, you know give us a chance, because then everyone would be saying ... they're putting diabetes on instead of seeing people with cancer and dying with heart trouble.' (Small white group.)

Improving information about food

Participants discussed at length their extent of knowledge about food and how that knowledge is

Table 2. Demographics of the focus group participants.

| | |
|--|-------------------|
| Male (n) | 19 |
| Female (n) | 20 |
| Mean age, years (range) | 58 (36–80) |
| Mean Townsend score ^a (range) | 3.79 (-5.70–8.31) |
| Mean length of time with diabetes, years (range) | 11 (1–26) |
| Current treatment (n) | |
| Insulin ^b | 22 |
| Oral medication | 13 |
| Diet only | 4 |

^aTownsend Score: high positive scores indicate higher levels of deprivation, high negative scores indicate higher levels of affluence. ^bSome patients were taking metformin in addition to insulin.

not well applied by people with diabetes. There were discussions about the food industry's labelling of food, which was often difficult to understand — particularly with regard to sugar content — in a way that would be helpful to people with diabetes and their families. Again pubs, restaurants and cafes were mentioned for not informing people with diabetes about the suitability of their menus. Culturally specific foods were even more difficult to get information about:

'I've been a diabetic for 22 years and I don't know if there is sugar in such things as cabbage and things.' (Larger white group.)

'Of course they can, they can do a lot for us by producing more sugar-free products.' (Asian male group.)

'I would like to see a counter, a shelf at least with good quality food for people with diabetes.' (Mixed group.)

'Yes suitable for vegetarians but nothing very often will say suitable for diabetics.' (Small white group.)

'Now this country is multicultural okay and there's just one type of food for diabetes and its English.' (Mixed group.)

One-to-one support

Participants valued the one-to-one support of their health professionals or family and friends.

'My family encourage me ... my friends cook for me healthy food, she always lectures me about consequences of diabetic.' (African-Caribbean group.)

'My family do a lot, they deprive me of all the foods I want to eat ... [they] encourage me to eat healthy.' (Asian female group.)

'The doctor is very important to me ... he really tell me to come visit him once a month ... I look forward to that, that's all I live for.' (African-Caribbean group.)

Health services

Many aspects about delivery of health services were discussed. Access to specialist services, patient-centred care and a culturally and linguistically appropriate service was suggested:

'He [the doctor] said, "You're getting worse". There should be a place where he said, "Right, the expert [is] here to tell you how to go on". And so you haven't got anywhere else to go apart from your doctor.' (African-Caribbean group.)

'You're on the waiting list for chiropody ... you may as well go somewhere else like Boots and have to pay that extra just to have your feet done good and proper.' (Small white group.)

'... if your weight and your blood pressure and everything was monitored a little bit more ... she [the practice nurse] says "I'll see you in 3 months" ... I thought, "Bloody hell, a lot can happen in 3 months".' (Mixed group.)

'The nurse used to check the diabetes but no advice was given.' (Asian male group.)

'We need bilingual people working for the health service who can communicate with us.' (Asian male group.)

'People who can speak English can ask for help and advice but those who can't will only benefit from what is told to them.' (Asian female group.)

'I was fasting in Ramadan. I used to eat buttered chapattis in the morning and was fine all day. I think it was my faith. The doctor told me not to fast.' (Asian female group.)

Prevention and screening

Prevention was also discussed at length. Firstly participants were concerned about the increased risks of diabetes in their children, and particularly concerned about the increased risk associated with childhood obesity. Secondly, screening for diabetes in high-risk populations was seen as important:

'But schools need to be educated.' (Larger white group.)

'Plus the children do because my son he just eats and eats and eats and he just won't have it that he could become diabetic.' (Larger white group.)

'... the one thing I would like is more education of eating right for younger people so my little boy doesn't turn out to have a problem like I have when I'm 32.' (Mixed group.)

'Why cannot children have tests, free tests to see whether they're getting diabetic or whether it's leading up.' (Mixed group.)

'And the family ... because we're both diabetic and we've got four children, will they get it?' (Larger white group.)

Difficulties of comorbidity

Participants recognised that the presence of other illness made looking after their diabetes more difficult:

'I try to eat well and take on exercise. I try to walk as much as I possibly can, but I have back pain: my doctor knows I can't walk for long periods.' (Asian female group.)

The value of exercise

Participants in some groups described how exercise and activity had a positive role to play in the management of their illness:

'Exercise, I think exercise is very important. You should do as much exercise as possible.' (Asian male group.)

'In fact these gyms and places should have a list of names of local diabetics, so they can contact them and invite them to free access.' (Asian male group.)

Self-management

Participants discussed the self-management of their condition. Many felt that patients should take responsibility for their condition but some participants appeared to deny the real consequences of diabetes, even to the serious detriment of their health:

'I think you have to be disciplined about your diet.' (Asian male group.)

'At functions you can't tell organisers to make special dietary arrangements for you.' (Asian male group.)

Table 3. Comparison of research priorities from the Research Advisory Committee for the Department of Health and the Medical Research Council and our findings.

| Research priorities of the Research Advisory Committee ^a | Research priorities from our focus groups ^b |
|---|--|
| Pancreatic b-cell biology and insulin secretion | Quality and consistency of information |
| Insulin action and insulin resistance | Raising awareness in the general public |
| Causes of diabetes (particularly genetic and epidemiological studies) | Improving information about food and diet |
| Obesity | One-to-one support |
| Prevention of diabetes | Health services |
| Screening for diabetes | Prevention and screening for diabetes |
| Patient self-management ^c | Problems of co-morbidity |
| Complications of diabetes | Exercise |
| Service organisation and delivery | Self-management (taking responsibility for yourself, denial about seriousness of diabetes) |

^aMain headings, ordered as given in the Research Advisory Committee documentation.

^bOrdered according to the importance identified during the focus groups and validated by the analysis process. ^cIncludes understanding prior beliefs of particular communities.

'As women, we do the cooking so its easier to be in control of your diet.' (Asian female group.)

'I don't think I do enough for myself, yet I know what I should be doing.' (Asian female group.)

'He's [the doctor] saying to you, "I'm prescribing medication that keep you alive." It doesn't help you most of the time, it just keeps you like that.' (African-Caribbean group.)

Some people even denied the existence of their diabetes:

'I'm not on insulin. According to me, the way I look at it, I haven't got diabetes.' (Mixed group.)

Summary of the findings from the focus groups

The research themes that arose from the important aspects of the focus group discussions, and further developed in discussion between the research team and two of the participants, are shown in Table 1.

Comparisons with the Research Advisory Committee

Table 3 shows the main themes of research priorities from the Research Advisory Committee and compares these with our main findings. It can be seen that there are no medical or science based themes in our study. Our participants placed less importance on prevention and treatment of complications of diabetes; however, there were many similarities in service delivery-based

research themes and in prevention and screening for diabetes. Our participants placed more importance on receiving information and achieving a better understanding of foodstuffs.

DISCUSSION

Summary of main findings

These findings show that the research priorities of people with diabetes are related to those aspects where the condition directly impinges on their ability to have 'normal' lives. Three key research themes emerged from the focus groups: information and awareness, service delivery and primary prevention. Such themes reflect the need for people with diabetes to understand and make sense of their condition, their need to use health and social care services and their concerns for their children and future generations.

Comparison with existing literature

When these themes were compared with those of the expert driven Research Advisory Committee³ there was a degree of overlap. Research Advisory Committee themes Service organisation and delivery, Prevention of diabetes and Screening equated to our themes of Health Services and Prevention and Screening. Research Advisory Committee themes: Patient self-management; Understanding prior beliefs of particular communities; and Obesity were all raised by our research participants as important aspects of research across several of our themes.

There were also considerable differences between our findings and those of the Research Advisory Committee, specifically, a noticeable lack of science based topics in our findings. The participants in this study never discussed, despite prompting, research about molecular and cellular biology and the clinical science fields.

In 2000, Diabetes UK also carried out a series of consultation exercises¹³ that they used to inform the government of their priorities for the forthcoming National Service Framework. Although most of their findings were based on consultation with committee members rather than hard to reach groups with diabetes, their priorities were closer to our own. Their key themes for research were Information and Education, Equality, Access and Standards. They also found that scientific-based research was not a priority.

There appears to be a definite difference between expert driven research agendas and those led by people who live with diabetes. This difference may be attributed to the fact that lay people do not always appreciate or understand the scientific basis of diabetes and its potential to

change their lives. Scientific research that makes a dramatic impact on people's lives is infrequent. The influence of research findings on changing clinical care is often perceived by the patient in different ways to health professionals.

Our objective for multicultural focus groups was to identify the mutual concerns and also the diversity of views that might have existed between the communities. The study revealed significant commonality in the views of the different cultural groups, but also showed differences between them that were influenced by culture. This raised research questions directly related to such cultural differences. While the Research Advisory Committee research agenda makes reference to the need for interventions to be designed for the particular circumstances of certain groups in order to assist with encouraging self-management of their diabetes, it does not identify any research questions pertinent to specific cultural groups. Five research questions in our findings are directly related to this important issue and so may contribute to establishing which research is relevant and important for particular cultural groups.

Strengths and limitations of this study

Our findings have complemented and extended the understanding of consumer-led research priorities described by Diabetes UK.¹³ Our research, in particular, gives people in an inner city area a voice and adds a multicultural dimension. We did not have a perspective from other groups of people with diabetes that may have different priorities and emphasis.

It is possible that the questions asked of the participants in the focus groups may have influenced the themes that we found, however the scope of our findings fits with other research involving consumers,¹⁴ which suggested that this is not the case. By public involvement at several stages of the research process, we feel we have increased the validity of the findings. Our important findings were often discussed in several of the focus groups without prompting and were again emphasised by the participants involved in the discussion of the analysis.

We have realised that research of this nature is both time consuming and difficult to carry out. Graham *et al*¹⁵ have described similar difficulties in their article about involving patients in public health research. It is not known whether many public perspectives should be explored to establish research priorities in health issues in general, as we do not know how much of an influence this would have and for what benefits or at what costs.

Implications for future research

This study raises important dilemmas for the current political priority of involving the public¹⁶ in all aspects of the NHS including research.¹⁷

If scarce research resources are to be funnelled towards addressing an expert-led research agenda on diabetes, with its predominantly scientific priorities, then patient satisfaction is likely to be low. On the other hand, investment in a programme of patient-identified research is more likely to generate consumer satisfaction. It is not clear how many user perspectives should be taken into consideration and at what cost.

Our research demonstrated some divergence between expert-led and patient-led agendas in NHS research. Using a participatory approach with patients we have identified a research agenda that has both similarities and differences with that proposed by the Department of Health. This approach has added further insight to this research agenda; however, it also raised questions regarding the issues of user involvement as a whole. Individual patients' perspectives have an influence on how they prioritise research and these perspectives are likely to vary. We do not know how many patients' perspectives need to be taken into account. Further exploration and development of methods to account for different patients' perspectives in setting research agendas may be worthwhile.

Funding body

This study was made possible by funding from Trent Focus 'Designated Research Team' funding and a grant from Trent Focus for supporting pilot projects in primary care research (no reference number used by funding body)

Ethical approval

Granted from Nottingham Research Ethics Committee (Ref No P1090201). Research governance approval granted by Broxtowe and Hucknall Primary Care Trust, Research and Development Department on behalf of Nottingham City Primary Care Trust (same Ref No)

Competing interests

Jane Dyas is an employee of Trent Focus, an NHS organisation that promotes development of research capacity in primary care in the Trent region of the UK, which also funded this study. She is one of the main authors of this study, which is appropriate for her role in Trent Focus, which is to work with new researchers to develop their research into actual projects and to support them throughout the research process

Acknowledgements

Gill Peck, specialist diabetic nurse, helped recruit patients to the study and ensured smooth running of the focus groups. Josephine Peat, Diabetes UK, Nottingham, helped develop the research question and suggested ways of accessing potential participants. Caroline Kenyon, Diabetes UK, helped analyse the data and presented the findings to colleagues and at conferences. Michelle Hubbard, Self-Help Nottingham, helped develop the research question and suggested ways of accessing potential participants. David Murphy, diabetic service-user, helped analyse the data and presented findings at

conferences. Zubeda Sarwar, Asian link-worker, helped develop the research question and suggested ways of accessing potential participants. Helen Kelly, practice nurse, helped recruit participants for the study. Professor Nigel Mathers, Trent Focus, Sheffield, critically appraised drafts of this paper and suggested improvements. Sarah Rodgers proof read the final draft and suggested improvements.

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