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Pre-diabetes in the elderly and the see-saw model of paternalism

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Received 11 June 2020

Revised 29 September 2020

Accepted 2 October 2020

Published Online First

4 November 2020

ABSTRACT

Pre-diabetes is a risk factor for the development of diabetes, not a disease in its own right. The prevalence increases with age and reaches nearly 50% of those aged over 75 years in the USA. While lifestyle modification and treatment are likely to benefit those with many years of life ahead of them, they are unlikely to benefit patients with a limited life expectancy. Despite this, some very elderly patients in the UK and elsewhere are being labelled as pre-diabetic. While ideal practice would be to carefully consider the impact of any potentially abnormal blood test before it is taken, this is not always possible in routine practice. In this paper, we discuss a pragmatic, ethical approach for clinicians managing pre-diabetic blood tests in very elderly patients. We argue that a 'see-saw' model of paternalism should be used in deciding which patients to inform that they can be labelled as pre-diabetic. Those patients that may benefit from the label should be informed, and those that will not, should not. Where the benefits/drawbacks are unclear, the result and its potential significance should be discussed in depth with the individual patient. We do not advocate withholding information from any patient. Instead we suggest clinicians use individual patient circumstances to contextualise the relevance of pre-diabetes to the patient and consider the benefits and drawbacks before informing them. This approach has the potential to be used for other pre-conditions and risk factors in addition to pre-diabetes.

INTRODUCTION

In the last decade there has been a marked increase in patients labelled with pre-diabetes in the UK.¹ The 'diagnosis' of pre-diabetes is made on the basis of a patient having one or more markers of abnormal blood glucose. Levels are higher than normal but have not reached the threshold where the patient gets diagnosed as diabetic. Patients with blood sugar levels in a pre-diabetic range are asymptomatic and disease free. The rationale behind labelling patients as pre-diabetic is that patients with pre-diabetes are at higher risk of going on to develop type 2 diabetes.² Type 2 diabetes can cause significant mortality and morbidity.³ There is evidence that lifestyle change (altered diet and increased physical activity) in patients with pre-diabetes can prevent progression to diabetes.⁴ Although patients may be labelled as 'pre-diabetic', and this might look like a diagnosis of a pathological condition, pre-diabetes is a risk factor for the development of diabetes, not a disease in its own right.⁵

Pre-diabetes is highly prevalent in Western countries. Its prevalence rises with age, and by age 75 years nearly 50% of the population in the USA is classified as pre-diabetic or diabetic.^{6,7} However, not

all patients with pre-diabetes will develop diabetes. The risk of a person with pre-diabetes progressing to diabetes within 12 months is between 1 in 10 and 1 in 20.⁸ This annual conversion rate drops even lower as patients age.⁹ A 12-year follow-up of older adults with pre-diabetes, showed most remained stable or reverted to normal blood sugar levels, whereas only one-third developed diabetes or died.¹⁰

If a person develops diabetes, they do not automatically develop symptoms or complications. Complications, such as retinopathy and renal disease, develop over time and are more likely to occur the longer a patient has suffered with diabetes.¹¹ Therefore, if a patient is approaching the end of their life, developing type 2 diabetes may have no direct impact on their health or quality of life.

In order for a patient to eventually benefit from the label of pre-diabetes they must fulfil three criteria. They must:

1. Be in the group of patients that are going to convert from pre-diabetes to diabetes.
2. Be in the group of patients that are going to develop symptoms or complications of diabetes.
3. Be in the group of patients for whom lifestyle changes or medication can prevent the conversion from pre-diabetes to diabetes.

If a patient does not belong to all three of these groups then labelling them as pre-diabetic will not confer any benefit to them. As conversion rates from pre-diabetes to diabetes reduce as a person ages and shortening life expectancy (which inevitably comes with ageing) reduces the risk of developing complications from diabetes, there is going to be a point in any patient's life, even assuming that lifestyle changes could prevent progression to diabetes, where a patient will not benefit from knowing they have pre-diabetes. Calculating the exact age at which that will occur for an individual patient is problematic but certain general principles can be established to help clinicians decide on the benefit of labelling.

This paper explores the pros and cons of a pre-diabetes label and a pragmatic ethical approach that could be taken by clinicians when faced with a new unanticipated pre-diabetic blood result that has been discovered through 'routine' blood tests.

WHAT ARE THE HARMS OF A PRE-DIABETES LABEL?

The treatment for pre-diabetes is, in essence, adopting a healthier diet and taking more exercise. If adopted and maintained, these lifestyle changes are likely to benefit most patients in



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To cite: Burch P, Holm S. *J Med Ethics* 2021;**47**:719–721.

multiple aspects of health, not just their risk of developing diabetes. However, although they may slightly delay the point at which a patient develops diabetes, studies of lifestyle-based diabetes prevention programmes show that most patients do not or cannot maintain long-term lifestyle changes.^{5,12} Weight loss is generally short term or minimal and patients usually slip back into old habits and routines. While there is undoubtedly an argument for informing younger patients who may receive a benefit from knowing they have pre-diabetes, the harms of informing increase with age.

Many elderly patients with comorbidities may struggle to increase physical activity. Dietary change and attempts to lose weight after a certain age can have detrimental health effects.¹³ Labelling somebody as having a medical condition carries a psychological burden in itself, and being unable to engage in the behaviour change recommended may also have negative consequences, that is, engendering a feeling of being 'a failure'.¹⁴⁻¹⁶ If the label leads to further follow-up this may also place a burden on patients. There are also considerable implications for the use of health resources if the labelling of individuals as pre-diabetic requires further follow-up and intervention. Annual blood tests are standard (£6.42), subsequent general practitioner (GP) or nurse (£30) appointments to discuss results frequently take place as do referrals on to the national Diabetes Prevention Programme (£270).¹⁷ There are roughly 3 million people in the UK aged 80 years or over.¹⁸ If one-third of them have pre-diabetes and, of those, half have an annual blood test, a quarter have a GP appointment and one in eight get referred to the National Health Service (NHS) Diabetes Prevention Programme that is an annual cost of around £37 million.

WHAT IS IDEAL PRACTICE AND WHAT IS THE REALITY?

While some patients may have been tested following screening for being at risk of diabetes, in the UK most patients in whom pre-diabetes is diagnosed have blood sugar level tests carried out as part of a battery of other blood tests that are performed as part of annual chronic disease monitoring for conditions such as hypertension.¹⁹ The contents of the battery are determined by individual practices and usually based on guidance and payment targets issued by the NHS.²⁰ In theory, a patient should give informed consent before any test, including blood sugar and HbA1c testing. In reality many patients who are given a diagnosis of pre-diabetes are unaware that they had blood tests for diabetes/pre-diabetes.¹⁹ When checking blood glucose or HbA1c in an elderly patient, especially one without symptoms of diabetes, the clinician should talk through with them the potential outcomes of the test and the implications this may have to them. The patient can then make an informed decision as to whether they want to go ahead with testing or not. In routine clinical practice in the UK this happens rarely, if at all. This is likely due to the volume of blood testing, the automated nature of the process, the limited time a clinician has to devote to each individual patient and the priority that individual clinicians assign to such conversations.

As we discussed in a recent paper a more individualised approach to 'routine' blood tests needs to be taken.¹⁹ The utility of each test should be gauged for each patient as an individual, not as the average patient that has a particular disease. The reality, however, is that this change will, at best, be adopted slowly or, at worst, not at all. What then, should clinicians who are presented with a pre-diabetic blood result in an elderly patient do?

THE SEE-SAW MODEL OF PATERNALISM

When faced with a series of test results for a patient, clinicians exercise judgement about what they consider 'normal' or 'satisfactory'. They also exercise judgement in what they communicate to the patient about the results. In certain circumstances a patient may, for instance, have a mildly raised bilirubin or mildly decreased albumin and the clinician may file the result as 'satisfactory' and not inform the patient. Is this an act of paternalism or is it the act of a clinician filtering out the 'noise' that is generated from carrying out tests and using an individual patient's circumstances to contextualise what is 'normal'?

Should clinicians, therefore, assume that all new pre-diabetic blood results above a certain age should not be disclosed to patients? This is obviously an indefensible position as a general policy since patients have a right to information that concerns their health. However, while the blood result may be a factual piece of data, the labelling of a result as 'satisfactory', 'acceptable' or 'abnormal' is a clinical judgement. There is, in most circumstances, a moral obligation on the clinician to disclose to a patient that they are suffering with a disease. Pre-diabetes is not a disease and unless a patient fulfils the three criteria set out in the introduction to this paper the information is not likely to benefit the patient.

In younger patients, where the criteria related to a significant likelihood of progressing to diabetes with negative health effects are likely to be fulfilled, there is an onus on the clinician to inform patients they have pre-diabetes. In many younger patients it will be difficult to judge whether they fulfil the third criterion and can successfully change their lifestyle. In these cases the likely benefits of 'diagnosis' outweigh any potential drawback. However, as a patient ages and develops certain other comorbidities, a tipping point is reached where the criteria are very unlikely to be fulfilled and the harms of a 'diagnosis' will outweigh any potential benefits. At that point informing the patient becomes harmful and should arguably only be done if the patient explicitly requests the information.

Rather than having a full discussion of the pros and cons of a pre-diabetes label with each patient we would advocate a 'see-saw' model of paternalist considerations. Younger fitter patients are automatically informed of their pre-diabetes whether or not they have requested the information explicitly while those who are very elderly and have comorbidities and a limited life expectancy are not informed. In the middle is the group of patients for whom paternalism either way is not appropriate because the benefits and harms of a 'diagnosis' are uncertain. These patients in the middle of the see-saw are those for whom an in-depth discussion about the relevance and meaning of 'pre-diabetes' to them as an individual needs to take place, and also those patients where the blood test most strongly ought to have been discussed before it was performed.

It could be argued that a drawback to this approach is the effect that it may have on patient-physician trust. In modern medicine patients are frequently seen by multiple clinicians. Clinician one may choose, quite ethically, not to reveal to a patient that they are pre-diabetic. The patient may then see clinician two who tells them. This could then create a situation where the patient loses trust in clinician one and, indeed, the whole medical profession. However, pre-diabetes is not a disease state. The non-disclosure of pre-diabetes is markedly different to the non-disclosure of a disease. If the patient understands that clinician one did not disclose to them because pre-diabetes is a risk factor that is not relevant to them, and not a disease, then, hopefully, there would be no loss of trust. In primary care in the UK, there is frequently

non-disclosure of other 'pre' conditions, such as chronic kidney disease.²¹ This non-disclosure takes place where the condition is of relevance to the patient and full disclosure would, generally, be in the best interest of the patient. This is ethically and professionally problematic. However, the response of patients who find out about non-disclosure in these cases is of interest. When interviewed, the response of patients to finding out about these non-disclosures is nuanced and varied.²¹ It does need lead to automatic loss of trust in the medical profession.

WIDER USE OF THIS APPROACH?

The purpose of the paper is to outline principles that could be applied, in an ethical manner to an unexpected blood test result of pre-diabetes. In theory, the principles outlined could be more widely applicable in other pre-conditions and other risk factors. To be applicable, a condition must have a fairly predictable trajectory, have a point where 'pre-disease' becomes 'actual disease' and be potentially reversible (or delayable). The principles could possibly be applied to early chronic kidney disease or early hypertension but may not be appropriate for other conditions or risk factors. The difficulty in other conditions is predicting whether a patient is going to convert from a pre-condition to a disease state, predicting when they are going to convert and predicting whether this is going to cause harm. In these cases, where there is doubt, this should always be discussed fully with the patient.

CONCLUSION

We have outlined a pragmatic ethical approach that can be used to guide a clinician when deciding how to manage an unexpected pre-diabetic blood result in an elderly patient. We argue that, while patients should have full access to all information and test results, pre-diabetes is a risk state, not a disease, and is only of relevance to patients that fulfil certain criteria. While the individual characteristics of each patient should always be considered, in general, those patients that do not fulfil these criteria should not be burdened or potentially harmed by being labelled. Where there is any doubt about the harms and benefits of a pre-diabetes label, full disclosure and open discussion should take place with the patient. This will help avoid a situation where trust in the medical profession is eroded when a patient finds out at a later date that they 'had pre-diabetes' and were not informed.

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Contributors The manuscript was primarily prepared by PB with alterations and additional material added by SH.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement There are no data in this work.

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