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## Title

The impact of pre-diabetes diagnosis on behaviour change: an integrative literature review.

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Key points:

1. Type 2 diabetes can be preventable.
2. Diagnosis of pre-diabetes or at risk status may enable behaviour change.
3. Increased provision of education and support is required to motivate lifestyle change in the person with pre-diabetes.

Key words: Type 2 diabetes; pre-diabetes; motivation; lifestyle; education; support

## Abstract

Type 2 diabetes is a growing global problem that not only affects individuals but has an impact upon the economic health of countries 1 . The number of people developing type 2 diabetes can be reduced by up to by 80%; this can be achieved by targeting those who are “at risk” 2. This reduction can be achieved by appropriate lifestyle changes to diet and physical activity 3. It is not known what the impact of being informed that you have pre-diabetes has on a patients motivation to make appropriate lifestyle changes.

The aim of this study was to assess whether having the diagnosis of pre-diabetes encourages or empowers people to make appropriate lifestyle changes to prevent progression to a diagnosis of type 2 diabetes.

Using a systematic approach, an integrative literature review was undertaken, using a standard retrieval and appraisal method. The studies demonstrated that pre-diabetes was found to be a challenging concept by patients and nurse alike. Lack of knowledge and support, along with patient’s perceived barriers had an impact upon the various motivation and self-efficacy behaviours towards lifestyle changes.

The integrative review found that more education and support is required to motivate lifestyle change in the person with pre-diabetes. This however does not need to be medicine led; use of peer and community based programmes could be not only cheaper, but also have the ability to provide potentially long-term support for people, and would provide continued reduced risk. Intervention needs to ensure that it is provided at an appropriate level to account for cultural, social and gender needs. Innovative approaches need to be considered to reduce the number of people who are diagnosed with pre-diabetes from progressing to type 2 diabetes and its associated potential complications.

## Background

It is acknowledged that Type 2 diabetes is a major health issue worldwide and is at current pandemic levels<sup>1,2</sup>. The causes of Type 2 diabetes are multifaceted, although not all the causes are fully known or understood. It is recognised that obesity and/or a reduction in physical activities are the main causes of type 2 diabetes<sup>3</sup>. Type 2 diabetes can cause poor health outcomes and early death. There is available clinical evidence that type 2 diabetes can be prevented in up to 80% of cases via lifestyle changes<sup>4</sup>.

The United Nations (2006/7) via a resolution, set the agenda for combating what it described as the “diabetes pandemic” by encouraging nations to develop effective policies to prevent, organise care and treatment of type 2 diabetes, which was reiterated by the WHO 2013 publication; diabetes plan to prevent the development of Type 2 diabetes. However surveillance and screening programmes are not uniformly applied or accessed consistently in European countries<sup>5</sup>.

Lifestyle changes can reduce the risk for high risk patients of developing Type 2 diabetes by between 25% and 72%<sup>6</sup>. The Diabetes Prevention Programme was a multi centred research programme (2009) that established that weight loss and increased activity can reduce risk. This was mirrored in the Finish Diabetes Prevention Study<sup>7</sup>. The Healthy Living Partnership to prevent diabetes (HELP PD) demonstrated that community based groups could also achieve a reduction in risk<sup>8</sup>. There is evidence that demonstrates appropriate lifestyle changes can prevent, and in some cases return the high risk person, to a normal HbA1c<sup>4</sup>. Empowerment has long been advocated as means to enable lifestyle change, encompassing behaviour change and motivational theory and initiating the desired shift of responsibility from the nurse to the patient<sup>9, 10, 11, 12</sup>. There has been some recent debate in the use of the term ‘pre-diabetes’ or alternatively ‘at risk of diabetes’. The current prevention guidelines refer to people at risk of type 2 diabetes, however patient information sources continue to use the term pre-diabetes interchangeably with ‘at risk’,<sup>28, 29</sup>.

## Integrative Review Methods

A systematic search was conducted in CINAHL, Embase and MEDLINE, databases, using Boolean combinations of search terms: pre-diabetes, lifestyle, behaviour, diagnosis, change, prevention, empowerment and Type 2 diabetes.

### **Inclusion criteria**

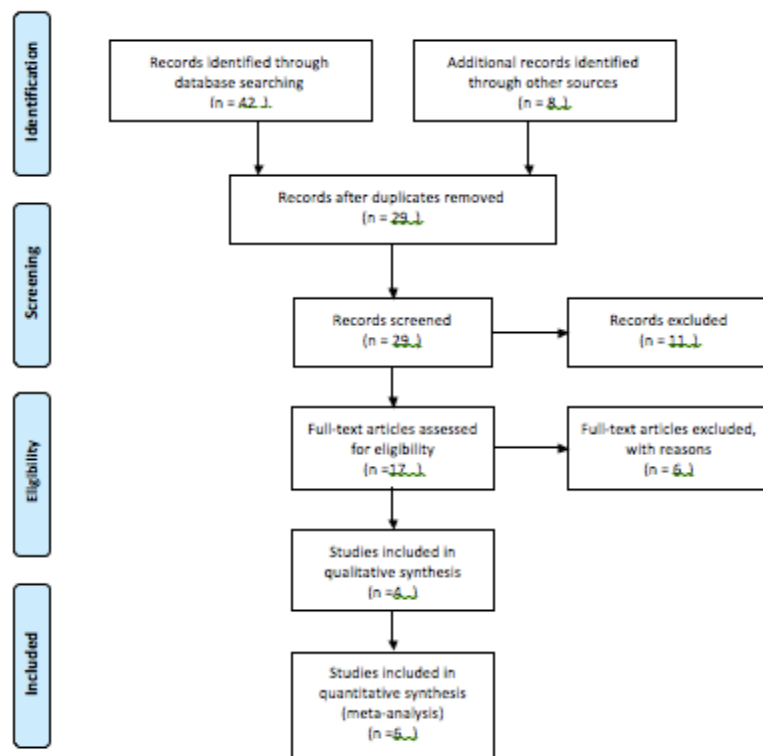
1. The search was limited to studies undertaken since 2001, as this was when the National Service Framework for diabetes was published, and this was the first policy in the UK that advised that there was a need to prevent Type 2 diabetes. Using this date limitation also ensured that it would be more relevant to present practice (Hewitt-Taylor 2011).
2. Only full text articles written or already translated in English were used, as there was no time or financial aid to get others translated.
3. Only articles with pre-diabetes and lifestyle changes were considered as it is the effect of that diagnosis that it being evaluated.
4. Only primary sources were used, to reduce the risk of inaccurate or biased reporting by the author (Aveyard 2010).
5. Only literature that is applicable to the research question was reviewed to prevent time being wasted on inappropriate studies (Whitaker, Wray 2006).
6. Quantitative and Qualitative studies to provide an encompassing view of the research question (Hewitt-Taylor 2011).

### **Exclusion criteria**

1. Drug treatment for pre-diabetes will not be included as it is lifestyle changes that are being considered to answer the research question. There are numerous studies that have looked at certain medications to prevent Type 2 diabetes that have been of benefit.
2. Impaired glucose tolerance, Impaired fasting glucose and risk of diabetes were excluded as this review is only concerned with the actual phrase "pre-diabetes"

3. Other chronic conditions for which lifestyle changes are deemed important i.e. diabetes, chronic heart disease and other diseases with lifestyle interventions advised, as it is the impact of pre-diabetes that is being considered.
4. Studies that were not available in English.
5. Articles written before 2001.

The PRISMA flow diagram (figure 3) shows the number of articles found on the databases. The quality of the studies were reviewed to ensure that they had been undertaken in a rigorous, valid and reproducible manner.



As both quantitative and qualitative studies were reviewed, the Critical Appraisal Skills Programme (CASP 2015) tool enabled the articles to be assessed critically for appropriate evidence in a logical robust manner that reduced bias and ensured that there was equity for the different approaches as it is specifically designed to enable us to understand scientific evidence about health. The CASP scores for each research study reviewed are detailed in Table 1. Following the scoring, the reviewed papers were discussed by the research team to enable the integration and identification of the themed findings.

## Findings

### **Understanding the impact of Pre-Diabetes upon a person**

There has been little work specifically done on the impact on a person of being informed that they have pre-diabetes 15. Feelings of uncertainty about the disease, its management and physical consequences affect a person emotionally and socially. Lifestyle changes were seen as a struggle, therefore changes to lifestyle were only undertaken if these did not impact on daily routines and habits 15, 16.

Overall it was found that being informed that a person had pre-diabetes, caused a radical change to how they viewed themselves and their health, which was sufficient to make appropriate lifestyle changes 22. Those who are motivated, accept that individual responsibility is essential to make lifestyle changes and therefore become responsible for their own health 16. Modifying lifestyle changes can be enormously difficult to achieve and maintain. Continued motivational input is necessary otherwise the lifestyle changes will wane 17, 19,23. However motivating self efficacy with support can be effective in enabling lifestyle changes as there is an increase in self confidence 17, 20, 21,23.

The evidence demonstrated that lack of knowledge and understanding about pre-diabetes on diagnosis resulted in patients not recognising the importance of lifestyle changes even though there is a strong correlation between knowledge of pre-diabetes and adoption of healthy lifestyles 15, 18, 20, 23.



## **Empowerment or dis-empowerment in diagnosis of pre-diabetes**

Studies have explored issues of uncertainty in the perceptions of the definition and severity of a diagnosis of pre-diabetes, and this may affect a desired empowerment outcome in a person, leading to accessing services, support and enabling behaviour change 14, 21, 23. The lack of any physical symptoms can make a person question as to whether they actually have a health issue and subsequently do not perceive a need to change lifestyle behaviour 14, 20, 21. Some of this may well be as a result of how a person are informed of the diagnosis and the subsequent follow up that they receive 14, 17. Jallinoja et al (2008) observed that people can feel that any change is hopeless, thereby preventing even minor lifestyle changes, the perception that certain behavior appears to be too hard to break, and patients accepted that they would remain as they were, which Hindhede (2014) describes as 'fatalism'. Quiping & Oh (2012) observed in their participants a perception that, as food is a necessity for living, there can be feelings of anger and deprivation when they are advised to make changes to dietary intake.

Authors have described perceived barriers that may reduce the capability of making change and becoming self-efficient, in terms of guilt, mood, feelings of failure, isolation, 'sabotage' by family and friends, and lack of support, 15, 19, 21. Geiss et al (2010) found that a person's educational status had an effect upon the ability of a person being able to make changes. Yudkin et al (2014) argues that another barrier is the label of pre-diabetes, stating that it is not useful to the a person, as they may not go on to develop type 2 diabetes, although the lifestyle changes that are advised for this would, however, be of benefit.

It has been suggested that lifestyle change is best achieved within a support programme and also linked to the concept of self-efficacy 16, 17, 18, 20. Geiss et al (2010) state that different ethnic groups need to have different interventions to modify behavior. Self-efficacy underpins a persons ability to then make change to their lifestyles 18. However, even with this understanding, ambivalence was one of the underpinning themes that could be found in the studies 14, 15 20. Jallinojas et al (2008) self-governing group viewed lifestyle changes from a positive point of view. They had the ability to maintain self-control, planning for "treats" and prepared to manage unexpected social events. Chen & Lin (2010), state that people are prepared to undertake lifestyle changes if they perceive a threat to their health.

They suggest that it is more important to work initially on improving a person's self-efficacy, than changing lifestyle.

Hindhede (2014) was the only author who actively looked at the use of pre-diabetes and its impact upon a person to engage in appropriate lifestyle changes to reduce the risk of developing type 2 diabetes. Her focus group work with the healthcare professionals was interesting as they viewed it as a "weapon" to be used, to in effect, bully or shame a person into making lifestyle changes. The person with pre-diabetes felt that it altered their self-perception but that it encouraged self-efficacy. Unlike Yudkin (2014) who felt that making this new category was counter-productive, Hindhede (2014) felt that there were positive benefits to the person with pre-diabetes to be informed of their diagnosis.

Chen & Lin (2010) found in their study, that using a health promotion intervention to encourage lifestyle changes to reduce the risk of Type 2 diabetes is ineffective until the person with pre-diabetes actually recognises that they are at risk. They state that having self-efficacy has a strong relationship to being able to undertake change. There was a repeated finding from the studies that one of the main complaints voiced by the participants, that may have been likely for non-engagement in lifestyle changes, was the lack of structured advice and education about the diagnosis of pre-diabetes and the lack of ongoing support<sup>14, 15, 17, 18</sup>. The need for education is supported in the wider literature<sup>24, 25</sup>. and also in policy<sup>26, 27</sup>. Several of the studies found that the participants wanted to have regular follow up by their nurse<sup>15, 18, 20</sup>, however in Jallinoja et al's (2008) study they found that there was a contrary view, that on the one hand they expected nurse support, but rejected the suggestion of there being strict health care advice given.

Koenigsberg et al (2004) describes the effectiveness initially of individualised plans, however this is very time consuming within service provision. Group interventions have a positive effect upon a person with pre-diabetes ability to make lifestyle changes as their level of knowledge about pre-diabetes improves so does the ability to make lifestyle changes<sup>18, 19</sup>. To provide effective support for lifestyle changes it is important to understand what actually prevent patients from making appropriate lifestyle changes. Jallinoja et al (2008) describes how they found 3 different characteristic groups within their study and describe the hopeless, struggle and self-governing repertoire. It has also been shown that the more

barriers that a patient perceives they have, the less action they are prepared to undertake

19. Barriers that possibly are outside a person with pre-diabetes control, are that of education, gender and social status 17, 18, 20, 21, 22.

## **Discussion**

Since the WHO (2011) changed the testing criteria for Type 2 diabetes there has been some confusion about what to tell a person with pre-diabetes who do not have a normal HbA1c but who don't have Type 2 diabetes. Yudkin (2014) argues that it is unfair to use this as a diagnosis, as not all people with pre-diabetes will develop type 2 diabetes. However as found by Troughton et al (2010), Hindhede (2014) and Chen & Lin (2010) this can cause uncertainty for the person with pre-diabetes which can result in them taking no action to change lifestyle. The studies reviewed provide an insight into how behaviour change takes place when a person are given the diagnosis of pre-diabetes. However although there have been a significant number of studies that prove the need for change, there is very little primary research that has been undertaken to assess the impact the pre-diabetes on a patients behaviour. This is surprising as the evidence for appropriate lifestyle changes is established. One of the main findings was the need to appreciate the types of barriers that a person with pre-diabetes need to overcome .The need for appropriate education for the person with pre-diabetes was highlighted as all studies found that initially knowledge and understanding of pre-diabetes and lifestyle changes were low. Aligned to this was the need for support and interestingly this does not have to be the remit of the nurse. The use of the terms 'at risk of diabetes' and/or 'pre-diabetes' needs to be clarified into either; one term or; the deferential definition of both terms, so that it is clear to the person and to practitioners. In terms of how this impacts on the person, it could be viewed that the term 'pre-diabetes' infers an inevitable progression to diagnosis of type 2 diabetes, as opposed to using 'at risk' which may imply that the risk status can be reversed.

The new national diabetes prevention programme aims to reduce the incidence of Type 2 Diabetes 28. Whilst we recognise that a large part of Public Health initiatives may not be effective, with education being provided but with poor outcomes, the pilot studies being

undertaken using social networks within the new programme may improve outcomes. However more important than education, was the requirement that understanding the process of change, and the ability to bring about self-belief in a patient was the essential approach to produce and maintain healthy lifestyle choices.

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Table1: CASP scores for each research study reviewed.

CASP criteria	Troughton et al 2008	Jallinoja et al 2008	Koenigsberg et al 2004	Geiss et al 2010	Chen & Lin 2010	Critchley et al 2012	Zhou & Oh 2012	Hindhede 2014	Kolb et al 2015	Yudkin et al 2014
1	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
2	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
3	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
4	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
5	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
6	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
7	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
8	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
9	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
10	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
11	n/a	n/a	n/a	n/a	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	n/a	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	n/a