

“What do you know about your diabetes ?”

A study of teenagers and young adults’ understanding of their disease

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Introductio

As practitioners, our perception and comprehension of type 1 diabetes (T1D) gets very precise with medical and fundamental research. However, it is still a challenge to take care of adolescents and young adults with such a chronic disease that upsets an already complicated transitional period ...

Our objective in this study is to give voice to the adolescents and young adults by asking them open ended questions interrogating their knowledge about their disease. Our aim is to understand more precisely what is well understood, what is not, and what are their topics of interest. This would allow us to adapt our therapeutic education programs to the specific needs of these newly autonomous patients.

Methods

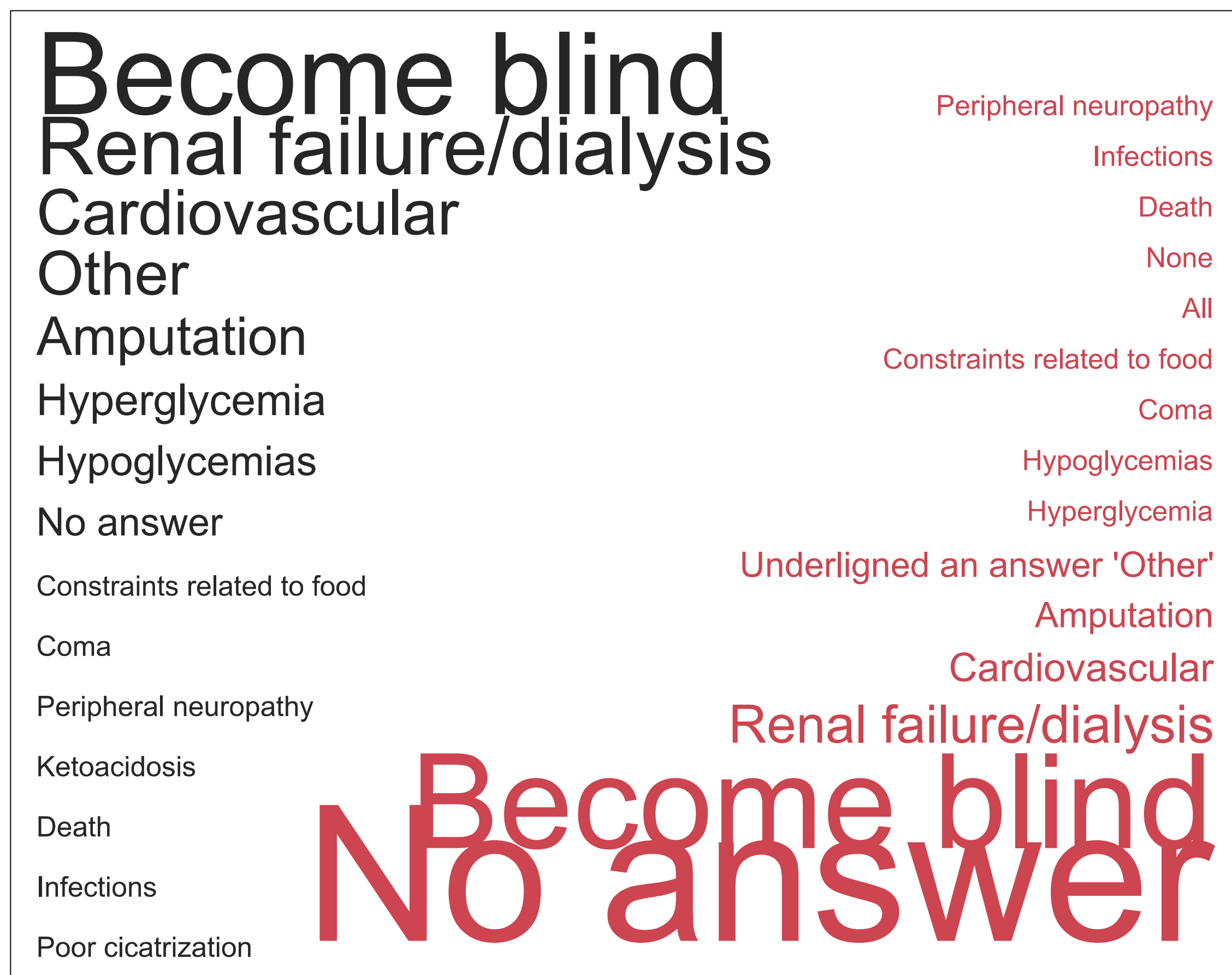
We displayed a questionnaire made of 35 questions including 22 open-ended questions about T1D, insulin, glycemia, nutrition, sports, contraception and fertility. Between May and November 2017 in the University Hospital of Bicêtre, we asked patients between 11 and 25 years old, either hospitalized or consulting their diabetes referent, to fill the questionnaire. A control of their HbA1c was systematic the day of the consult or the first day of their hospital stay. Their free answers were then grouped into categories and enabled us to make a qualitative and quantitative analysis.

Results

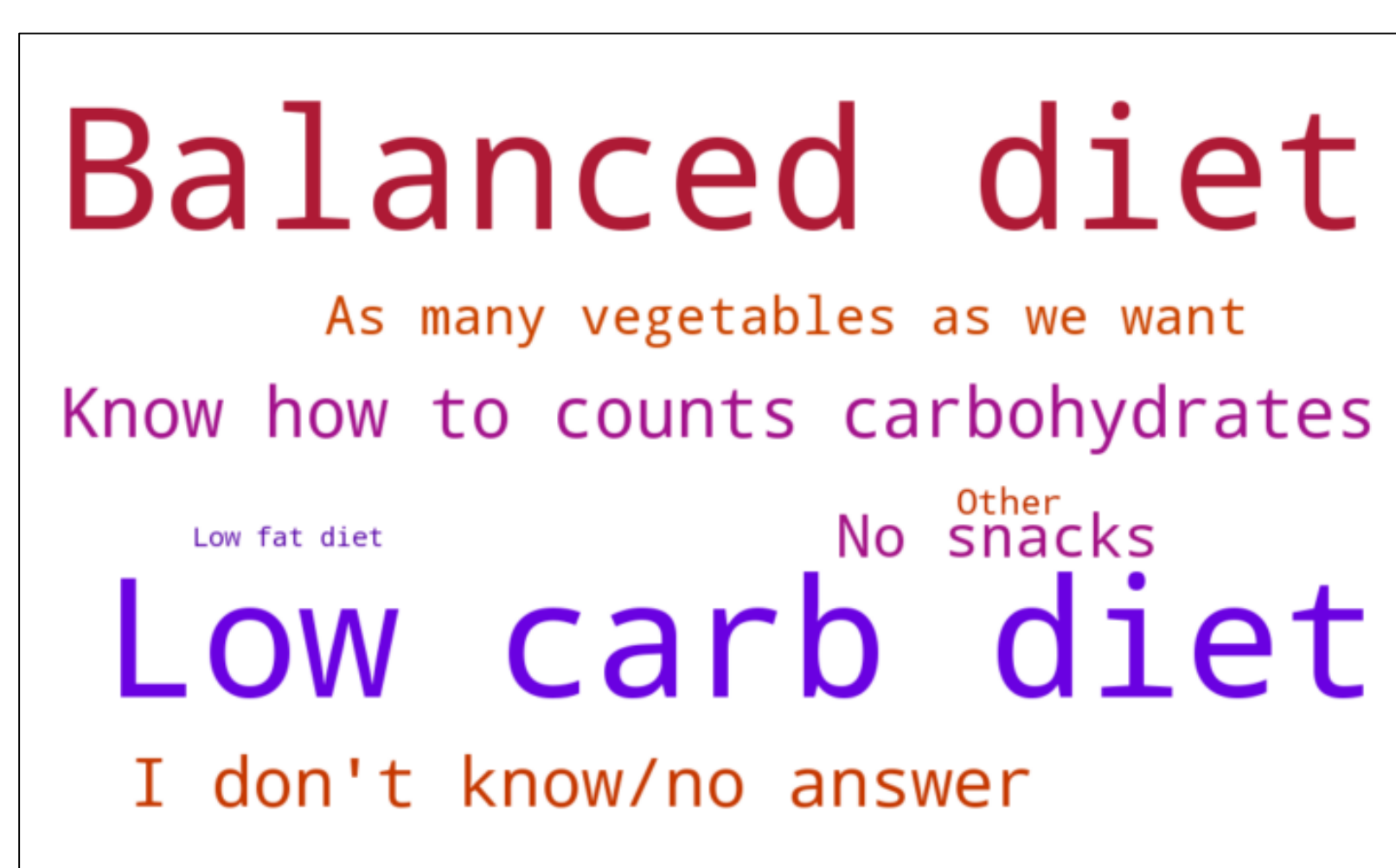
Cohort characteristics : 102 patients, mean age : 15,6 years, 60% of male and 40% of female. Their mean duration (+/- SD) of diabetes was 7,7 (+/- 4,1) years. 83,3% were autonomous on insulin injections/pump, 38,8% of the patients were on insulin pump. The mean HbA1c of the cohort was 8,7%.

What is well understood

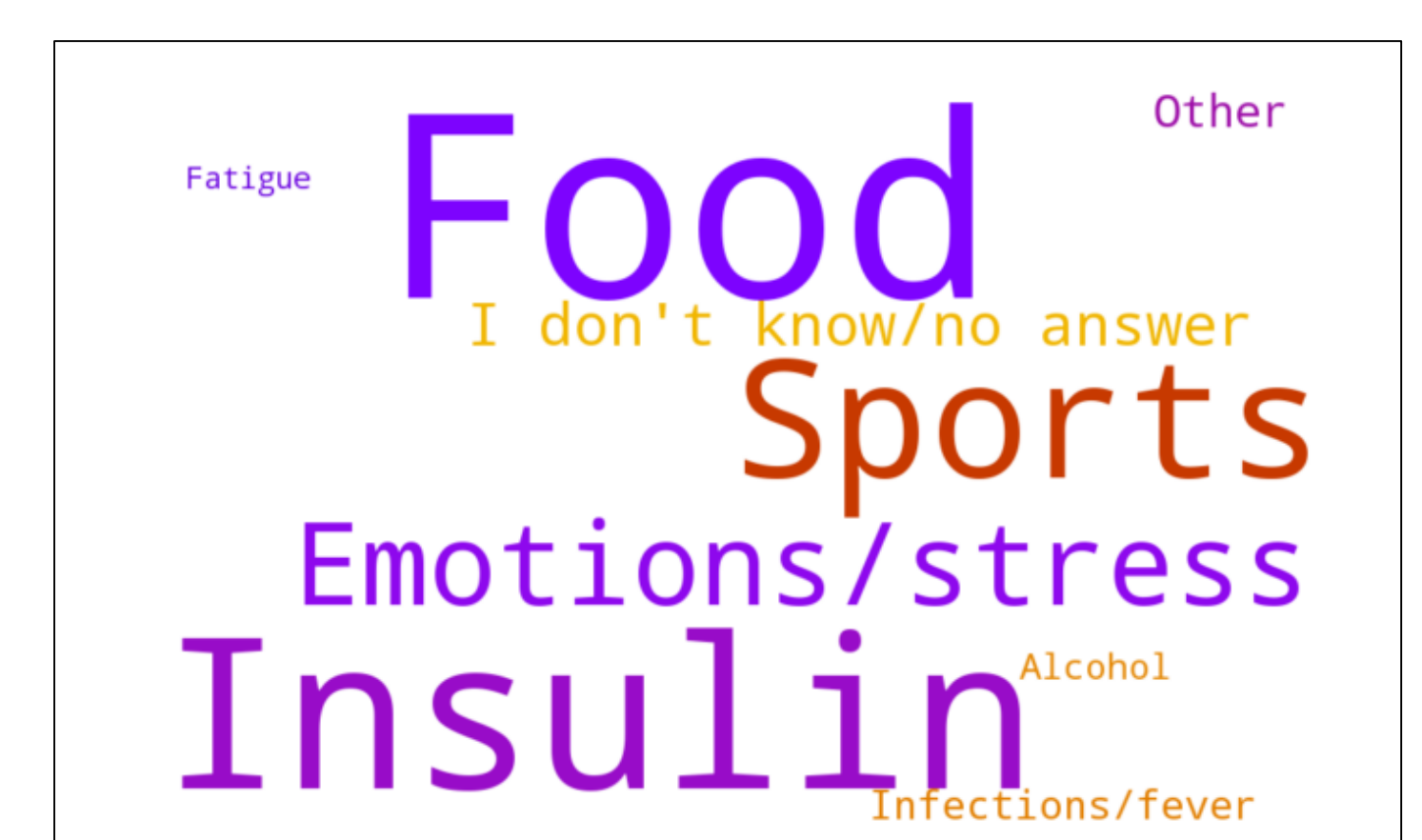
For you, what are the possible complications of T1D (words in black) ?
Please circle the one(s) you fear the most (words in red).



Could you describe the diet of someone with T1D?



What parameters cause glycaemia variation?

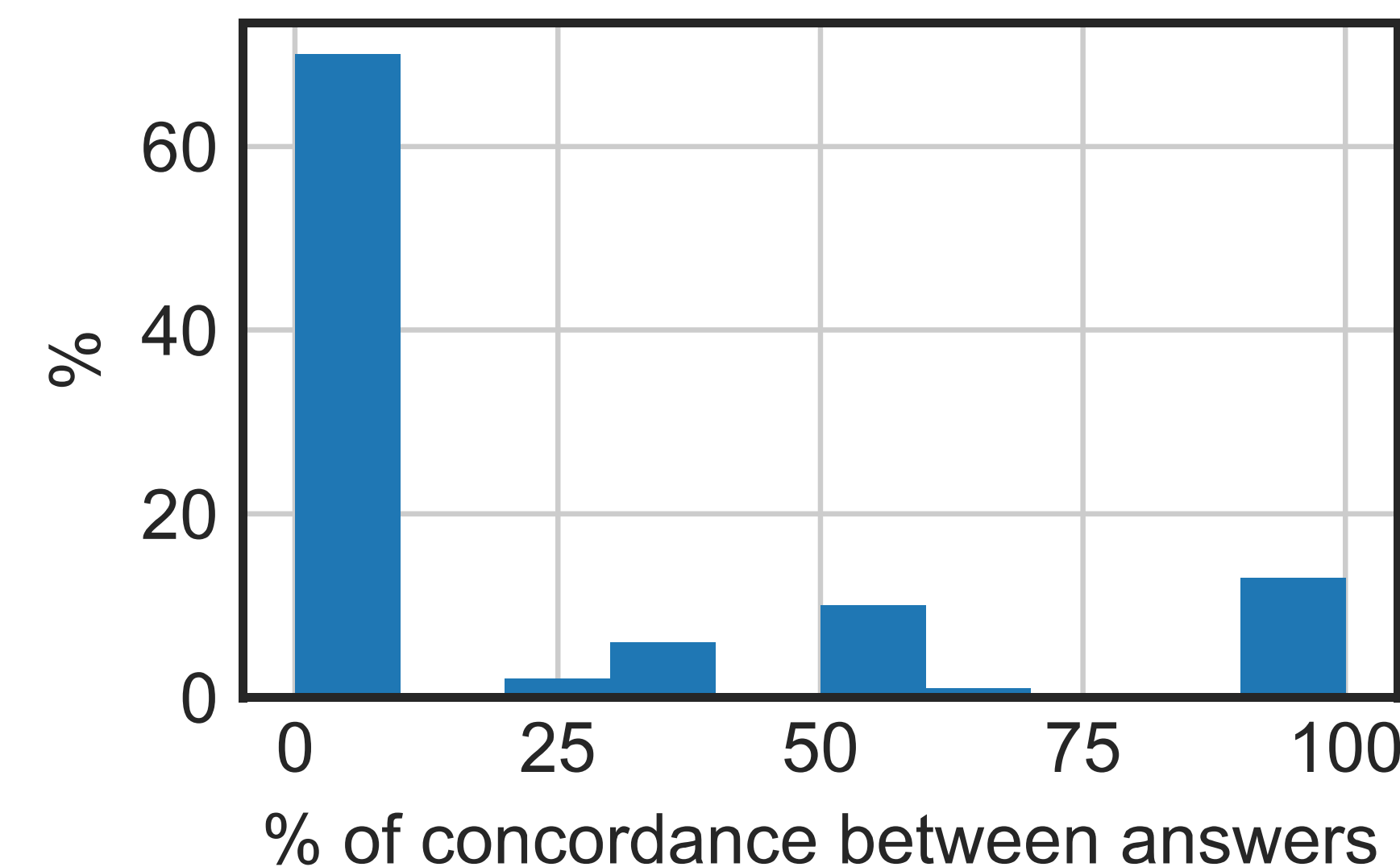


When the practice doesn't meet the theory...

Question 1: When should you control your glycaemia?
Exemple of answer 1: "When I wake up, when I change my pump, before a meal"

Question 2: When do you really control your glycaemia?
Exemple of answer 2 : "When I change my pump, when I feel weird, signs of hypoglycaemia".

% of concordance between answers : 33 %



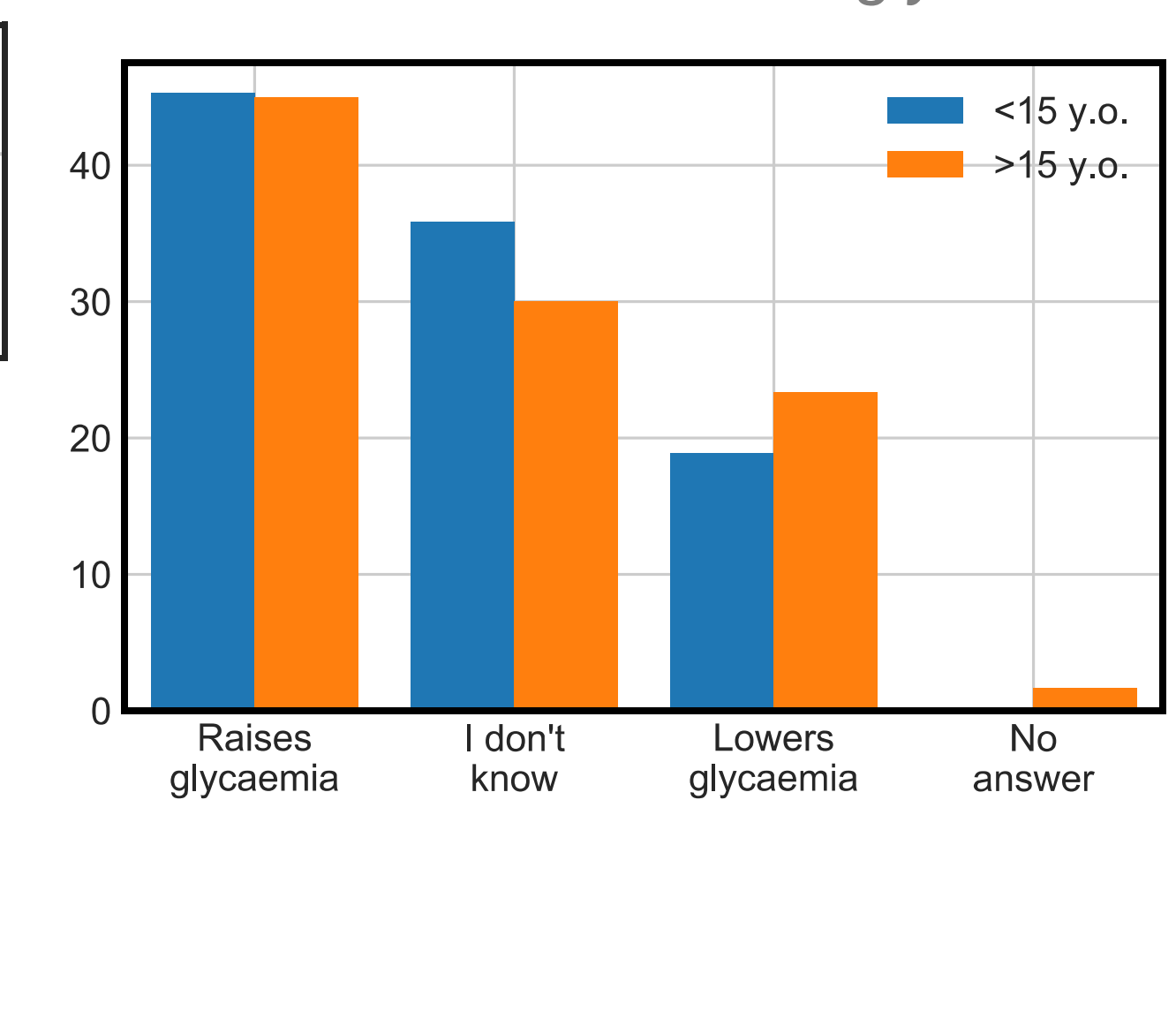
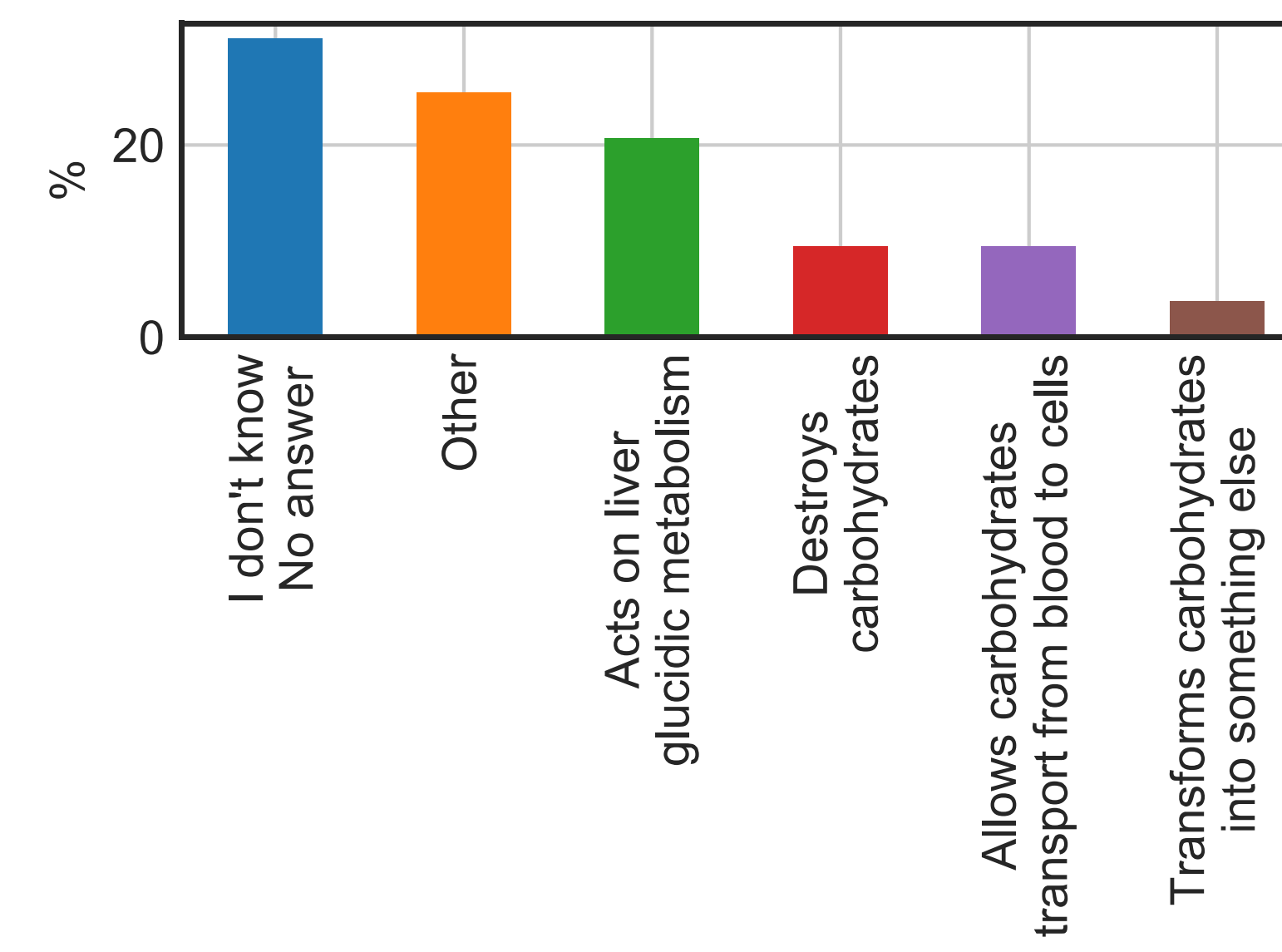
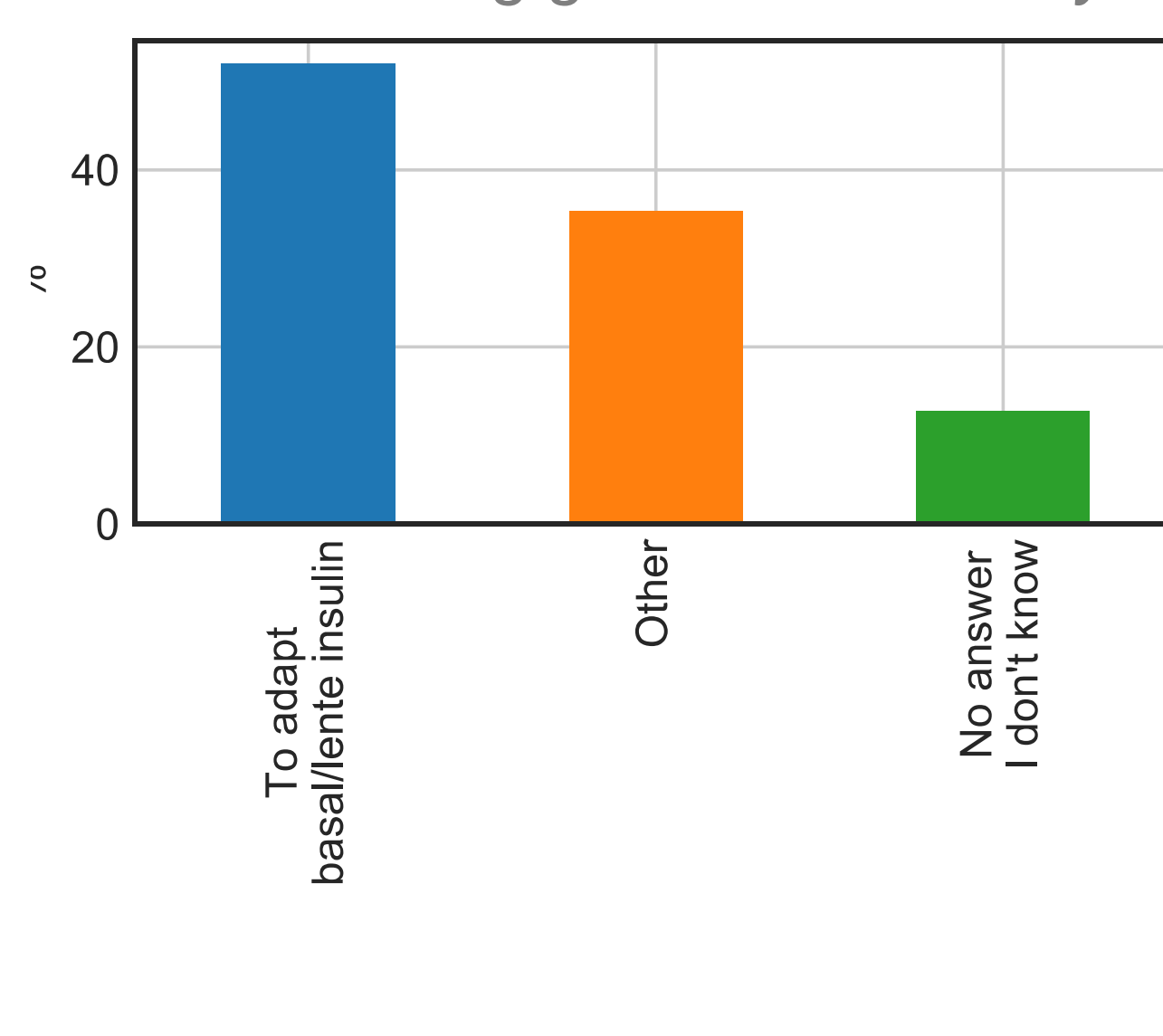
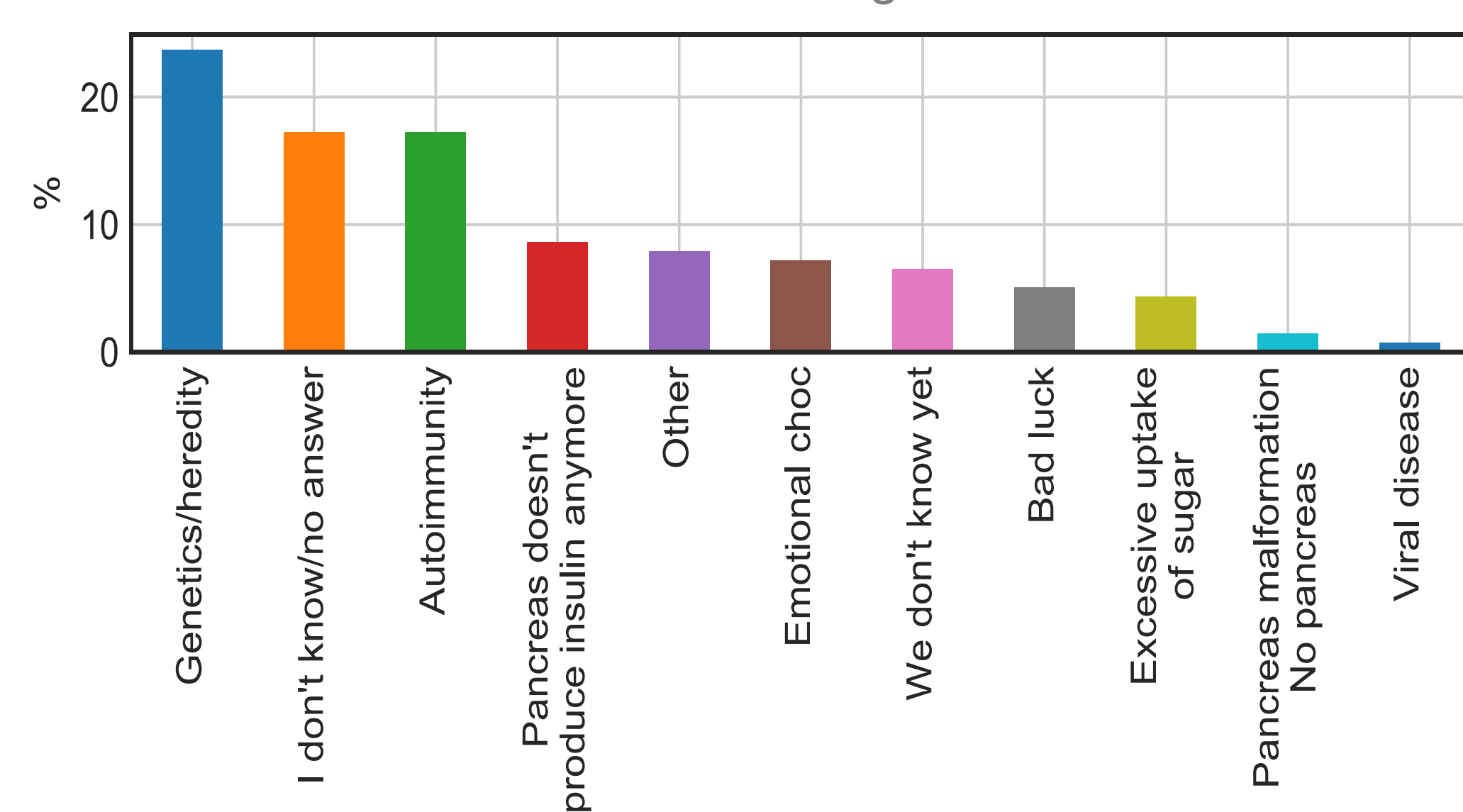
What could be improved

How does someone gets T1D?

What is fasting glucose necessary for?

What is the mecanism of action on insulin?

How does alcohol act on glycaemia?



Giving voice - through open ended questions - to adolescents and young adults with T1D allowed us to have an overview of their general knowledge about their disease:

1/ They have understood the importance of insulin, glycemic control and nutrition, but this knowledge doesn't prevent the inobservance of the treatment or its surveillance.

2/ The word "complication" can be misunderstood. Some patients understand "what is complicated with T1D" and their answers are related to food and injections constraints.

3/ Only 1/3rd of the population spontaneously quote autoimmunity when asked about the physiopathology of T1D. The population also shows difficulties to explain the mecanisms of action of insulin. They are not informed enough about the risk of hypoglycaemia with alcohol consumption.

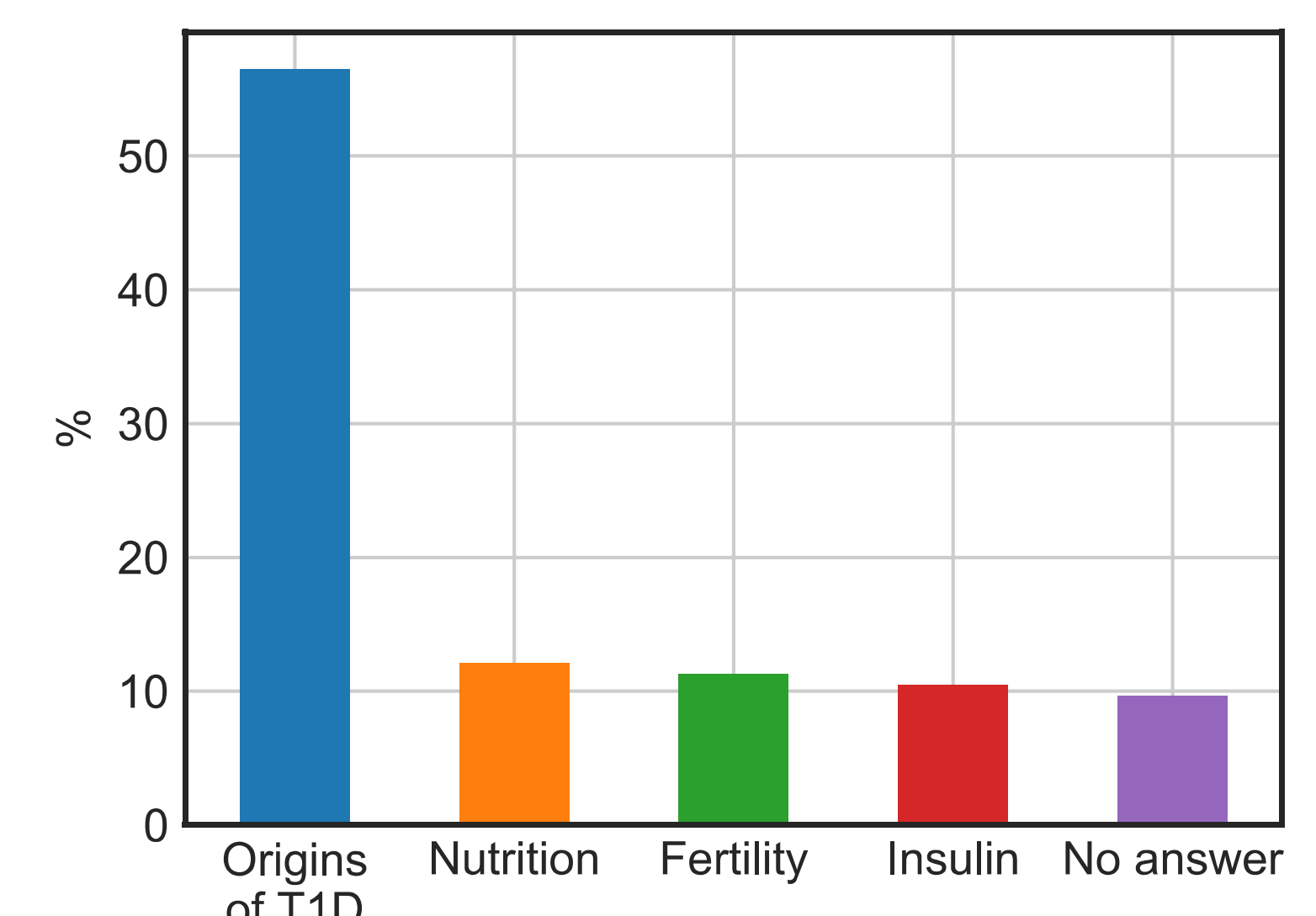
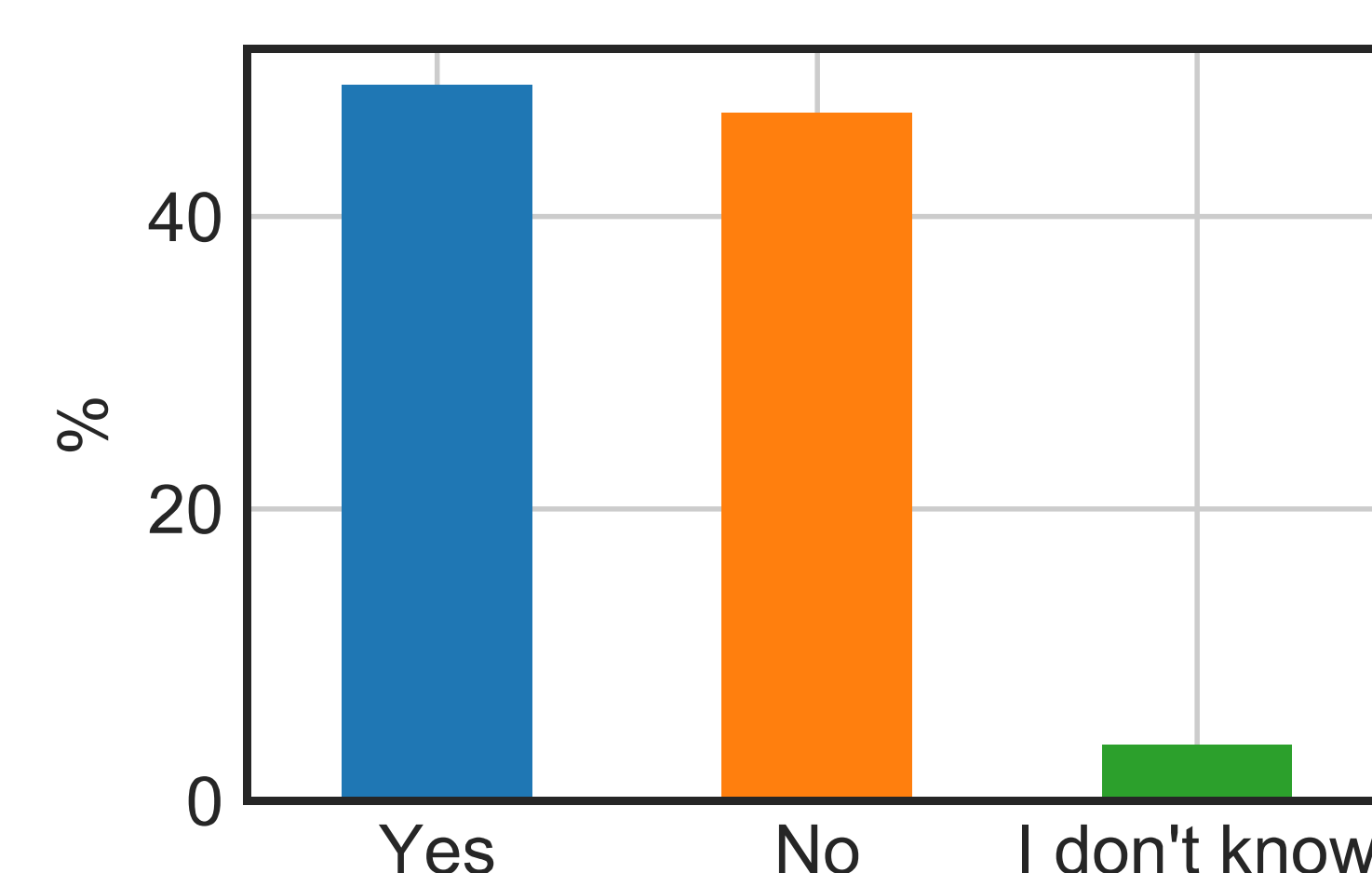
4/ When questionned about their topic of interest in T1D, the majority of the cohort chose "Origins of diabetes", which could encourage us to explain again that there are still some mecanisms we don't know in the apparition of their auto-immunity ...

Conclusion

What they wonder about

Do you fear to transmit T1D to your children?

What topic would you like to know better about?



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