



Experiences in obtaining prescribable and non-prescribable gluten-free products of adults with coeliac disease in Lothian.



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Introduction Coeliac Disease (CD) is a lifelong chronic disease of the small intestine affecting approximately 1% of the population, [1] which requires adherence to a gluten-free diet (GFD), yet strict adherence in adults is suggested to range from 42-91%. [2] Gluten-free products (GFP) are costly for the consumer, [3] thus within the UK a proportion of staple GFP on prescription to assist with dietary compliance. [4] Anecdotal evidence suggests that aspects of the current prescribing system are problematic, however there is a lack of published data regarding individuals' acquisition of GFP from the UK GF prescribing system and from the retail market which may be factors that underpin compliance. The aim of this study was to assess the experiences of Lothian Coeliac UK members (>18 years) in obtaining both prescribable and non-prescribable GFP.

Methods A questionnaire using both qualitative and quantitative questions was to ascertain individuals' experiences in obtaining prescribable and non-prescribable GFP. This was emailed to all members registered with a local Coeliac UK branch (Lothian, Scotland) (>18 years, N=863), (May-June 2010)

Results n=130 (RR15%); 43M: 87F; mean (SD) age 49 (14) years; median (IQR) age at diagnosis 43 (21) years 57% did not receive regular check-ups from health-care professionals; only 31% had regular check-up with a dietitian.

Table 1. Experiences of obtaining prescribable GF-products

| Stages in obtaining prescribable GF products | n | Convenient (%) | Inconvenient (%) | Discarded (%) (n/a or impartial) |
|--|-------|----------------|------------------|----------------------------------|
| Depositing a prescription at the chemist | n=122 | 69 | 8 | 23 |
| Requesting a prescription from the GP | n=122 | 62 | 24 | 14 |
| Collecting the GFP from the chemist | n=121 | 60 | 16 | 24 |
| Storing the GFP at home | n=123 | 54 | 36 | 10 |
| Amending the choice of prescribed products | n=123 | 31 | 49 | 20 |

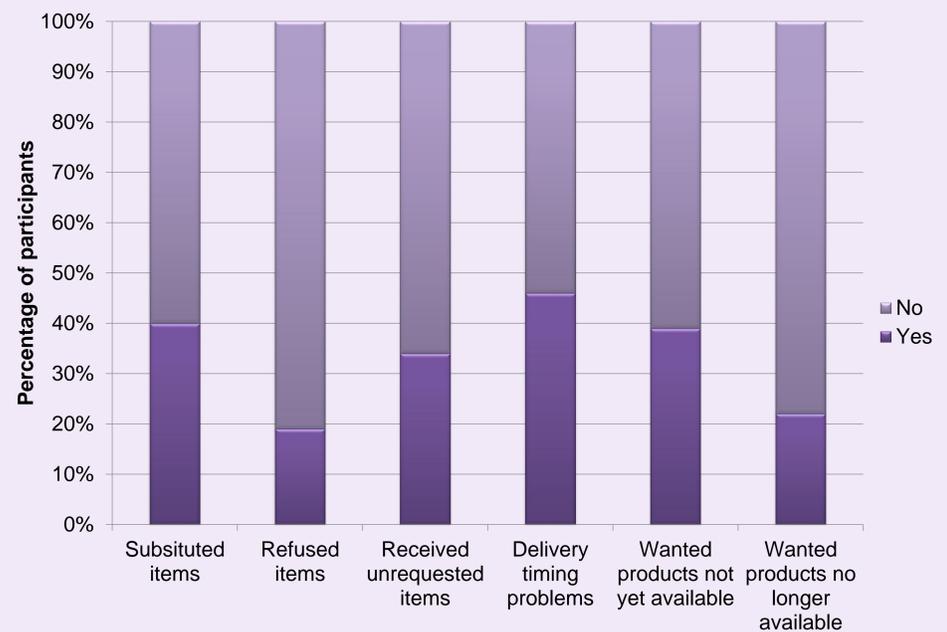


Figure 1. Experiences of obtaining prescribable GF-products

Experiences of current GFP prescribing system

Table 1 shows participants' experiences of the different stages of the current system, illustrating quite different experiences.

- Used by 88% of participants
- 38% felt the range of products available on prescription was inadequate with significant numbers reporting they were often refused items or received substituted or unrequested items (figure 1)
- Amending choice of items, delivery timing problems, transporting products home & storage of these were highlighted as significant problems.

Overall 2/3rds rated the system as convenient, whilst 19% felt it was inconvenient.

Experiences in obtaining non-prescribable GFP

- 91% had changed their shopping habits since being diagnosed, due to products' cost (14%), lack of choice (43%) and product availability (37%).
- 30% changed the supermarket at which they shop.

Supermarkets are the preferred location for shopping

- 47% rated the supermarket as inadequate in terms of choice of GFP

- 30% indicate they find food labelling difficult to understand.

Conclusion This study has shown that there are inequalities in individuals' experiences of the current prescribing system of GFP. Cost choice and availability of non-prescribable GFP are potential barriers to an easily accessible GFD.

References

- [1] Agency for Healthcare Research and Quality (2004) Evidence Report/Technology Assessment No. 104 Celiac Disease. AHRQ Publication No. 04-E029-2
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