Managing symptoms and health through self-prescribed restrictive diets: What can general practitioners learn from the phenomenon of wheat avoidance?

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Background and objectives

Seven per cent of Australian adults report avoiding wheat products for the relief of symptoms. The objective of this study was to explore the experiences, symptoms, influences and beliefs that may explain the tendency for this behaviour to occur predominantly in the absence of a reported medical diagnosis or expert dietary supervision.

Method

Data were collected through preliminary questionnaires and semi-structured interviews with 35 self-identified symptomatic individuals who avoid consumption of wheat-based products without a diagnosis of coeliac disease or wheat allergy.

Results

Like other contested health phenomena, symptomatic wheat avoidance is characterised by broad symptomatology, perceived benefits, absence of clear biological markers, dissatisfaction with conventional medicine following previous negative test results, and the fact that presumed treatment – elimination of a dietary factor – requires no medical intervention.

Discussion

Self-prescribed food avoidance represents a diagnostic and therapeutic challenge for practitioners, central to which is a tension between patient expectations and biomedical standards of evidence in the diagnostic relationship.

It is well known that ingestion of certain foods can cause adverse reactions in some predisposed individuals. Among the most recognised conditions are those associated with wheat: coeliac disease and wheat allergy. While the prevalence rate for each condition is estimated at approximately 1% of the general population,[1,2] the proportion of individuals who report avoiding wheat products because of perceived ill effects is far greater. In a recent national survey, 7% of adults (not counting apparent coeliac disease cases) reported consciously avoiding wheat products because of a range of adverse symptoms, primarily gastrointestinal, which they attributed to the consumption of wheat.[3] Few participants in the survey reported a formally diagnosed sensitivity. More than half cited no medical influence in the decision to avoid wheat, and non-clinical sources of information – complementary medical practitioners, friends and the media – were prominent influences.[3]

Self-diagnosis and self-management by patients of symptoms risk delays in the identification and treatment of other potential underlying organic conditions,[4] and the possibility of dietary deficiencies caused by unnecessarily restrictive diets.[5,6] For medical practitioners, this signals the need for greater understanding of the experiences and diagnostic processes that lead to this behaviour, including factors underlying the circumventing of mainstream medicine. These questions were addressed in a questionnaire and interview study of a sample of self-identified symptomatic individuals who avoid wheat.

Methods

Participants were recruited using identical advertisements placed in four local community papers targeting the greater metropolitan and hills area around Adelaide, South Australia. The advertisements, headed 'Do you avoid wheat?', invited adults

who were actively avoiding consumption of wheat-based products to participate in a study. Participation was described as the completion of a questionnaire, and a possible invitation 'to be interviewed about [their] experiences and have a dietary assessment'.

A study information sheet, consent form and preliminary questionnaire were sent to individuals who expressed interest in the study (n = 70) during the two-week recruitment period. Responses to the preliminary questionnaire were used to screen for study eligibility, resulting in the selection of 35 participants.

Inclusion criteria were age 18 years or older, experience of adverse reactions they associated with the consumption of wheat, and willingness to attend the Commonwealth Scientific and Industrial Research Organisation's (CSIRO's) research clinic. Exclusion criteria were diagnosed coeliac disease or wheat allergy, and avoidance of wheat to manage a pre-existing medical condition. Attendance at the research clinic was required for the dietary component of the study (not reported here). Full-study participants received a $70 gift voucher for Myer at the conclusion of the study. Ethics approval was granted by the CSIRO Food, Animal and Health Sciences Human Research Low Risk Review Panel (reference number: LR08/2012).

Study design

Questionnaire

As well as assessing study eligibility for sample selection, the preliminary questionnaire collected demographic information and descriptive data around core avoidance behaviour:

- Length of avoidance
- Avoidance of other cereal grains (from a checklist, with scope for additions)
- Reported intolerances to other 'non-grain' foods or food components
- Key symptoms associated with wheat consumption
- Any diagnoses requiring the elimination or reduction of wheat from the diet.

Except where noted and for demographic data, questions used an open-ended response format. Only data collected from the 35 full-study participants are reported here.

Interviews

Most of the data were gathered through semi-structured, one-on-one interviews conducted either face-to-face or over the telephone at the convenience of the participants. Prior to sample recruitment, pilot interviews were conducted with three known wheat avoiders, and the final interview questions were refined on the basis of these pilot interviews. Each interview lasted between 30 and 80 minutes, and was digitally recorded. The interviews followed a script in terms of the issues to be addressed and questions to be answered, but allowed the interviewer flexibility to probe for greater clarity where needed. The interviews focused on key influences and experiences leading to the decision to avoid wheat; the flexibility, challenges and perceived health benefits of a wheat-avoidance diet; symptoms experienced (from a 22-item checklist with scope for additions) and participants' thoughts on why the consumption of wheat causes adverse reactions.

Recordings of interviews were transcribed verbatim and the transcripts imported into Dedoose (www.dedoose.com), a web-based program that assists with the management, retrieval and presentation of qualitative and mixed-methods data. Familiarisation with the data and identification of key themes were carried out by two authors (SG, NC), who independently reviewed seven transcripts and then discussed and agreed upon a coding framework. The coding framework was then applied independently to three further transcripts to test for inter-rater agreement. This resulted in a pooled Cohen's kappa of 0.76, where values >0.75 may be taken to represent excellent or substantial agreement beyond chance.[7,8] Given the nature of the data, the themes thus identified are reported without precise quantification of their incidence, and illustrative quotations are provided in parentheses.

Results

Participants

Demographic and avoidance characteristics

Thirty-five self-identified symptomatic individuals who avoided wheat (31 women, 4 men), ranging in age from 33 to 83 years (mean = 54.1 years; standard deviation = 12.5) agreed to participate in the study. Sample characteristics are summarised in Table 1. Participants were generally well educated, with 25 (71.4%) reporting having a tertiary qualification. Reported histories of wheat avoidance ranged from four months to 20 years, with a mean of approximately six years. Seven participants

Table 1. Sample characteristics (n = 35)

Sex	**n (%)**
Female	31 (88.6)
Male	4 (11.4)
Age	**n (%)**
30–40 years	5 (14.3)
41–50 years	9 (25.7)
51–60 years	8 (22.9)
61–70 years	9 (25.7)
≥71 years	4 (11.4)
Education	**n (%)**
High school	5 (14.3)
Technical or trade certificate	5 (14.3)
University or tertiary qualification	25 (71.4)
Length of avoidance	**n (%)**
≤1 year	8 (22.9)
>1–5 years	10 (28.6)
>5–10 years	9 (25.7)
>10 years	7 (20.0)

reported wheat as the only grain they avoided, 15 reported also avoiding other grains that contained gluten, and 13 reported avoiding one or more other non-gluten cereal grains (eg rice, corn, millet) in addition to wheat. Participants also indicated avoiding or limiting dairy-based foods (n = 18), processed or 'unhealthy' foods (n = 14), some fruits or vegetables (n = 7), sugar (n = 7) and red meat (n = 5). More than half (n = 19) reported additional, often multiple, food sensitivities or intolerances, with dairy (n = 10) the most frequent.

Symptoms reported

Reactions attributed to wheat, noted either at the preliminary questionnaire or administration of the symptom checklist during the interview, are listed in Table 2. These most frequently involved gastrointestinal discomfort, with all but one participant indicating bloating or wind. All participants reported gastrointestinal symptoms, a majority reported tiredness, and headaches were also common; otherwise, Table 2 shows considerable variability, including a number of idiosyncratic responses.

Interview data

Key influences

Participants were asked who or what had been influential for them in making the connection between wheat and how they were feeling. On the basis of responses, participants were classified into three categories of practitioner involvement.

1. Influence of medical practitioners

Nearly one-quarter of participants cited a suggestion from a general or specialist medical practitioner as the basis for their avoidance of wheat products.

> *I had an endoscopy and the surgeon … was able to say that coeliac was negative and he just, on consultation with him, said he is finding more and more people, if they abstain from wheat, the symptoms go. Simply, almost his throwaway line at the end of the consultation after the endoscopy, because he said he couldn't find any gut-related problem and I wasn't coeliac.*

In some cases, these recommendations related to patients' symptoms; in others, they were of a more general nature, including weight control.

> *My other doctor … she said … 'Just don't eat wheat, it's bad for you. I don't eat it and I've found that my thinking's better, weight loss is better' and, you know, 'just avoid it'.*

No participant reported having received a formal medical diagnosis.

2. Influence of complementary medicine practitioners

Almost half of the participants cited a recommendation by a practitioner of complementary or alternative medicine.

> *The chemist had a naturopath there and I, just on a whim, I went in to see her and she suggested that I try an elimination diet to find out what my problem was. So she suggested that I cut out dairy and cut out wheat products and that sort of thing.*

With the exception of one person who identified the influence of both medical and complementary medicine practitioners, membership of these two categories did not overlap.

3. Lay influences

The remaining approximately one-third of participants reported no active practitioner involvement. Here, the most commonly mentioned influences were family and friends.

> *I have a sister with exactly the same symptoms. Between the two of us, we've probably worked out that that's what it appeared to be.*

Another commonly mentioned influence was the participants' own research.

> *I was just reading lots of information about dietary intake and stuff and I thought, 'Nup, I'm just going to cut out wheat and see how I go'.*

There were also some references to more incidental exposure to information through mass media.

Table 2. Symptoms attributed to consumption of wheat by participants (n = 35)

	n (%)
Bloating (fullness or flatulence)	34 (97.1)
Feeling sluggish or tired	25 (71.4)
Stomach discomfort or cramps	25 (71.4)
Abdominal pain	17 (48.6)
Headaches	15 (42.9)
Vomiting, nausea	13 (37.1)
Constipation	12 (34.3)
Cannot concentrate or think clearly	11 (31.4)
Heartburn or indigestion	10 (28.6)
Skin problems (eg eczema, itching or rashes)	10 (28.6)
Feeling sad or 'blue'	9 (25.7)
Mucus build-up	9 (25.7)
Body aches, pains or stiffness	8 (22.9)
Feeling anxious or nervous	7 (20.0)
Feeling irritable, angry or aggressive	7 (20.0)
Sleep disturbances	6 (17.1)
Breathing problems (wheezing or hyperventilating)	4 (11.4)
Sweating	4 (11.4)
Dizziness or vertigo	3 (8.6)
Abnormal bowel habits	2 (5.7)
Feeling unwell or bad	2 (5.7)
Hives	2 (5.7)
Fluid retention	1 (2.8)
Poor appetite	1 (2.8)
Oesophageal pain	1 (2.8)
Gut symptoms	1 (2.8)
Tongue swelling	1 (2.8)
Restless legs	1 (2.8)
Feel heavy	1 (2.8)
Rectal irritation	1 (2.8)
Heart palpitations	1 (2.8)
Tightness in chest	1 (2.8)

I mean, it was only some sort of article in the [Sunday paper] or something, one of those great journals, you know. But I just thought, 'I'll give that a go, why not?'.

Justifications

Among participants who cited extra-medical influences – especially complementary medicine – some reported having previously sought answers from conventional medicine without success. These people variously cited frustration with negative test results as factors leading them to seek alternative explanations or treatment options.

Invariably, going to see a GP and having blood tests and things done showed that there's no particular issues.

Another factor was dissatisfaction with diagnoses or treatments offered.

Because a lot of medical practitioners don't believe in intolerance, they only see things as an allergy ... if you haven't got the allergy therefore you don't have a problem.

For some other participants, taking the complementary medicine route reflected a philosophical leaning to alternative perspectives on health, described as eastern or holistic.

I think naturopaths do have one advantage in a sense in that they try to see the body and mind as a whole, they see how the pieces fit together.

Perceived benefits and challenges

Participants reported diverse, and often speedy, benefits of eliminating wheat, including:

- weight loss – *I think I actually lost something like 7 kg really, really quickly.*
- greater wellbeing – *Really, it was about two or three days, all of a sudden I just felt more alert, fresher, wide awake.*
- less fatigue – *I found immediately I was no longer wanting to sleep straight after eating.*
- reduced gastrointestinal symptoms – *I was like 'Gee, I'm not bloated anymore and oh, my gosh, I don't, you know, have so much loud flatulence.*

Although about one-quarter of the sample reported no real difficulties maintaining their diet, the majority recounted challenges relating, most commonly, to the availability of and search for suitable food options.

Flexibility of the diet

While some participants reported strict adherence to their wheat-free diet, the majority revealed some flexibility of approach, expressed in terms of selective avoidance (eg bread, cake, pasta), or the belief that reactions to wheat were dose-related. Examples of the latter were avoiding wheat 'if possible', permitting occasional indulgences, and eating wheat in the presence of others.

Theories of cause

Participants were asked what they thought might be causing or contributing to their adverse reactions to wheat. Responses fell into three broad categories.

1. Some aspect of wheat

The most commonly invoked theories related to over-exposure or over-consumption, and beliefs that wheat has been changed to enhance yield, pest resistance or food characteristics.

2. Individual differences

A widely expressed view was that a segment of the population is simply more susceptible to food-related issues; this was variously attributed to a genetic link, an inability to digest gluten, hormonal changes, or a heightened sensitivity of unknown origin.

3. The modern diet

Some participants expressed concern about the overly processed nature of modern diets, alluding to the heavy use of chemicals in processing and production as 'overloading' people's systems. A related theme linked growing levels of food intolerances to deficiencies in the modern diet.

Discussion

Recent research describing key features of self-prescribed food avoidance practices in Australia has raised concerns about the implications of this behaviour for public health and clinical practice,[3,9,10] and identified a need for closer examination of what underpins it. The participants in the present study were predominantly female and generally committed to avoiding wheat consumption. Although they should not be presumed to be a representative cross-section of Australian adults who avoid wheat – especially given their recruitment from a single state capital and its suburbs – the information they provided in interview is consistent with that obtained through the earlier population survey and can offer a level of elaboration not possible in the population survey. In particular, the close correspondence between the patterns of symptoms and influences reported, and those observed with the survey sample adds weight to the ability of these interview data to cast additional light on the survey findings, as intended.

Like wheat-avoiding individuals in the population survey, participants most commonly attributed gastrointestinal discomfort, and frequently attributed feelings of tiredness, to the ingestion of wheat, and demonstrated considerable diversity in their invocation of other symptoms.[3] This diversity in symptom patterns is consistent with previous observations of broad, 'permissive' accounts of symptoms – and thus of perceived improvements – in cases of self-diagnosis. It has been argued that the lack of boundaries around symptoms popularly associated with contested conditions offers an easy match for quite common symptoms and few grounds for exclusion.[11] Whatever the case, participants attributed rapid and often far-reaching benefits – well beyond the relief of gastrointestinal discomfort – to the dietary modification, which several described as life-changing.

Participants' lay explanations for why wheat should cause symptoms were

also varied and broadly divisible into external (something to do with modern wheat varieties or nature of the modern diet) and internal (something to do with me) attributions. These explanations typify the spectrum of concerns about wheat propagated in readily accessible information media,[12] and further caution against the assumption that avoidance of a food because of its perceived physiological effects necessarily equates to a perceived food intolerance.[9]

The interview data testify to the significant role that information from lay sources – personal research, acquaintances, mass media – and complementary medicine may play in important decisions about health and symptom management. Where the advice to avoid wheat for symptom control was ascribed to medical practitioners, it was depicted as a doctor's suggestion for something to try rather than a response to a positive diagnosis. Indeed, the inability of conventional biomedical procedures to generate a firm diagnosis was often mentioned by participants, including some whose avoidance of wheat was, nonetheless, at the recommendation of a doctor. Some of those who found the answers they sought in complementary medicine expressed their dissatisfaction at the inability of conventional medicine to diagnose their complaint; similar disaffection with aspects of biomedicine has been noted in people on gluten-free diets in America.[13]

The general lack of rigour in the decision processes described leaves open the possibility of alternative explanations for improvements attributed to the avoidance of wheat. Such explanations include the effects of specific, unidentified components of a dietary change, nocebo responding,[14–16] the still contested condition termed non-coeliac gluten sensitivity (NCGS),[17–19] intestinal malabsorbtion of short-chain carbohydrates (fermentable oligosaccharides, disaccharides, monosaccharides and polyols [FODMAPS]),[19,20] and effects of alpha-amylase/trypsin inhibitors.[21] However, none of these explanations lends itself to ready diagnosis. Moreover, the already challenging task of linking the alleviation of particular symptoms reliably to the elimination of specific food components is made more difficult where people avoid multiple dietary factors. A prime example of this behaviour is the common tendency for avoidance of wheat to be accompanied by avoidance of dairy foods,[3,9] which was also evident in the present sample.

While it may be easy to dismiss the avoidance of a dietary factor such as wheat as a fad, many participants presented as being sufficiently committed to the behaviour to endure a number of challenges and compromises, including limited product choice. Nevertheless, the need to avoid wheat or gluten often constituted a desirable but forgiving standard rather than an imperative, with the consequences of a transgression perceived to be proportionate to the extent of the transgression. Like those surrounding the self-diagnosis of coelica disease in a US study,[22] participants' accounts reveal a tension between biomedical and lay standards of evidence, where lay standards are characterised by a broad, accommodating symptom profile, reliance on extra-medical sources of information, and the perception of improvement in symptoms as confirmation of the correctness of a decision. To these we might add an accommodating causal profile that admits a number of possible culprit foods, often including dairy products. These determinations are made possible by the fact that the presumed treatment – the elimination of a dietary factor – requires no medical intervention.

Conclusions

Interviews with symptomatic participants who avoid wheat products depict the behaviour as commonly the result of successful dietary experimentation based on advice from complementary medicine practitioners, information from informal sources (eg acquaintances, media), or somewhat speculative suggestions from medical practitioners. Some participants' reported frustration at unsuccessful attempts to obtain a medical diagnosis for their symptoms signifies a mismatch between patient expectations of medicine and biomedical standards of evidence. Whether participants who avoid wheat are quite right, partially right or quite wrong in attributing their symptoms to the ingestion of wheat, the phenomenon presents multiple challenges for biomedicine. The same is likely to be true of dairy avoidance, which, although less commonly attributed to the influence of complementary medicine, exceeds wheat avoidance in prevalence.[9]

Implications for general practice

Self-prescribed food avoidance represents a clear diagnostic and therapeutic challenge for general practice as it does for public health initiatives that exhort individuals to engage with, and take responsibility for, their health. Central to that challenge in each case is the tension between patient expectations of diagnosis and treatment, and the biomedical standards of evidence that are assumed in public health programs and underpin clinical practice. One consequence of this tension is to render the avoidance of dietary factors for the control of symptoms substantially invisible to medical oversight. Given the proportion of individuals affected, the risk of underlying conditions going undiagnosed and the potential for nutritional imbalances, this is a phenomenon of which practitioners need to be generally aware in their interactions with patients. More directly, it identifies a potential dilemma for clinicians in how to cater to a patient's demand for answers about symptoms of gastrointestinal discomfort of indeterminate origin.

It is clear from interviewee accounts that some clinicians treat a negative test result as definitive, whereas others suggest subjective dietary experimentation. It is also clear that either

clinical experience may be a precursor to the decision by a patient to eliminate a dietary factor, although the likelihood of this outcome in either case is unknown. Where the two clinical approaches might be expected to differ is in patient satisfaction and clinician awareness of a patient's subsequent dietary modification. An alternative option for clinicians to consider is referral of patients with unexplained gastrointestinal symptoms to an accredited practising dietitian, whether for systematic trialling of a low FODMAP diet[23] or to monitor dietary adequacy in cases of dietary experimentation.

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