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Research Article

Daily Living and Healthcare Experiences of Individuals Living with Desmoid-Type Fibromatosis: A Qualitative Investigation

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Objective. Desmoid-type fibromatosis (DF), a rare benign tumour with similar treatment options to cancer, can adversely impact people's lives, yet little qualitative research addressing patients' experiences of DF exists. The present study aimed to understand the day-to-day experiences of individuals with DF and their experiences of healthcare. *Methods*. Semistructured, qualitative interviews were conducted by phone or email with 20 participants. Inductive thematic analysis was performed, structured with the Framework approach. *Results*. Many participants reported delays in diagnosis. This was attributed to them ignoring their symptoms or to healthcare professionals lacking awareness of DF. Healthcare experiences varied, with some participants expressing good support. Others felt unsupported, viewing staff as dismissive of difficulties. Comparisons between DF and cancer were commonly discussed. Some participants felt relieved that they did not have cancer; others perceived that their needs were secondary to cancer patients and believed they were treated as less important. Participants discussed negative impact of DF on psychosocial well-being. Chronic pain and activity limitations seemed to impact mood and relationships. *Conclusion*. Greater awareness and understanding of DF by health professionals may help to reduce diagnostic delay and improve support. Individuals may benefit from being treated by specialist DF teams.

1. Introduction

Desmoid-type fibromatosis (DF) is a rare noncancerous tumour [1]. Although benign, DF tumours can invade surrounding tissue, be challenging to control, and cause chronic pain and mobility limitations [2, 3]. Furthermore, pain has been associated with poor quality of life, depression, and functional impairments in individuals with DF [4]. Desmoid tumours are locally aggressive and regularly have a variable clinical course, resulting in unpredictable treatment outcomes [5]. Furthermore, the high recurrence rates following treatment have been found to lead to worry in many patients even after tumour removal [6]. DF can impact physical, social, and psychological aspects of an individual's life [5].

Individuals with DF are often treated by oncologists due to being offered similar treatments to individuals with cancer such as chemotherapy, radiotherapy, and surgery [7]. Some individuals do not appear to feel adequately supported [3], yet there is a lack of research aiming to understand how to better meet individuals' needs within healthcare services.

Research has mainly focused on medical aspects of DF, e.g., treatment effectiveness [8, 9]. Little research has aimed to understand the experiences of people with DF [3]. Husson et al. [3] conducted qualitative interviews and focus groups with individuals with DF recruited from a UK specialist

cancer hospital. They found that diagnostic delay could cause distress. Treatment pathways were described as challenging due to the idiosyncratic and unpredictable nature of DF tumours and treatment side effects. Participants worried about recurrence and increased physical restrictions. Pain and mobility limitations were reported as the most challenging aspects of DF. The authors concluded that the physical, psychological, and practical issues patients faced are complex and difficult to manage.

A focus group study conducted in the Netherlands also found that the diagnostic process caused distress for people with DF, but this was mainly due to fear of a cancer diagnosis, rather than due to diagnostic delay [6]. Participants worried about regrowth and seemingly struggled with self-esteem and body image. Participants also reported difficulties at work due to treatment side effects or taking time off for treatment. In addition, social changes regarding friendships were mentioned, with some friendships becoming stronger, but others finishing due to individuals feeling unsupported [6].

Whilst these studies provided valuable insight into patients' experiences, participants in both studies were recruited from single hospital sites; experiences of patients treated elsewhere could differ. Furthermore, links between healthcare staff and the research teams may have affected how open participants were willing to be about their experiences. The present study aimed to understand the day-to-day experiences of individuals with DF and their experiences of healthcare. Interviews were conducted with participants recruited through a UK national support group rather than from specific hospital sites, with an option of participating either via phone interview or email to enhance accessibility.

2. Methods

Ethical approval was granted by the University Research Ethics Committee 3 (2019-6812-10341).

2.1. Participants. Inclusion criteria were as follows: lived experience of DF, aged over 18 years, based in the UK at the time of the interview, and English-speaking. Adverts for the study were posted on Desmoid United UK's Facebook page and Sarcoma UK's website (UK-based DF support organisations). Recruitment ceased when no new issues were identified in interviews, suggesting data saturation had occurred.

2.2. Data Collection. Informed consent was obtained from participants prior to the interview. Semistructured interviews were conducted in July-August 2019, by phone or email according to participant preference. This approach was primarily followed in order to increase the accessibility of participating in the research. Conducting interviews by phone or email removed geographical barriers to participation. Furthermore, whilst phone interviews were conducted during standard working hours, with email interviews, participants were able to respond at any time to suit them. Conducting interviews via email also enables the collection of concise, well-thought-out answers, with participants having time to reflect and formulate responses. Furthermore, some participants may feel more comfortable discussing personal experiences via email, due to the anonymity afforded by the method [10].

As the research team includes a clinician, it was made clear that there was no direct link between data collection and healthcare staff, enabling participants to be open about their experiences. Interviews were guided by interview schedules covering the following: general experiences of living with DF, DF-related healthcare, treatment, and questions based on the Common Sense-Self-regulation Model (CSM: perceptions around timeline, cause, consequences, and treatment) (see appendix) [11, 12]. According to this model, people form illness representations about their medical conditions which integrate with existing schemata and beliefs. This enables people to make sense of their symptoms and guides coping behaviours.

For email interviews, the interview schedule was split into five blocks which were emailed to participants one at a time (see appendix). Participants were asked to complete question blocks within three working days. A reminder email was sent after this time. If no response was received after two weeks, participants were assumed to have withdrawn. Where more detailed responses were sought, the researcher asked participants to elaborate on specific answers before emailing the next block of questions. Phone interviews were audio-recorded and then transcribed verbatim. Email interview responses were copied into a Word document.

2.3. Analysis. A thematic analysis was conducted to facilitate an understanding of the thoughts, feelings, and experiences of participants [13]. Whilst the interview schedule contained questions based on the CSM, the analysis was inductive (not based on this model), with the researcher aiming to understand and communicate the thoughts and experiences that were important to the participants [14]. Analysis was completed from a critical realist epistemological stance, where truth is determined through an individual's subjective views [15].

The framework approach structured this inductive, thematic analysis [16]. Through the production of matrices summarising data ("charting"), comparisons were made both within and between participant responses [17]. This systematic approach enables other researchers to follow the analytic processes, review how interpretations of the data were reached, and contribute to the analysis process.

The analysis was led by the first author, who carried out familiarisation, coding, development of a working framework, indexing, and charting. The first and the last authors met regularly throughout the analysis process. The last author read a sample of interview transcripts, and analytic decisions were discussed at each stage. Key ideas from each transcript were noted in the margin and subsequently used to identify important and recurrent ideas ("codes") across the dataset. This coding enabled the development of an

initial working framework: a hierarchical list in which codes were organised into categories and subcategories. This working framework was used to index each transcript line-by-line: the researcher applied the working framework to the data, linking text to framework categories. Charts were created, within which interview content was organised by interview and framework category. The researchers used the charts to carefully and rigorously interrogate the dataset, examining the content of working categories across participants and interviewee responses across categories. Categories were reorganised within charts, such that those addressing similar issues were grouped together and developed into final themes. Categories that were not well supported within the dataset were not included in the final analysis.

3. Results

3.1. Participant Characteristics. Thirty-six individuals replied to the study advert. Four did not meet inclusion criteria; two could not participate due to hospitalisation; three withdrew without explanation; seven did not respond after receiving full study information. Twenty people (19 females and 1 male) aged 22–59 years (median: 35.5) participated in an interview. Table 1 shows the description of the participants.

Phone interviews ranged from 20 to 38 minutes (mean: 29 minutes). Email transcripts ranged from 896 to 4696 words (mean: 2382). Two email participants only completed the first block of questions.

3.2. Analytical Findings. Four themes were identified as follows: experiences of diagnosis and treatment, experiences of healthcare interactions, comparisons to cancer, and psychosocial impact.

3.2.1. Diagnosis and Treatment Experiences. Many participants found the diagnosis process difficult, with delay in diagnosis appearing as a common experience. Some participants attributed diagnostic delays to them misinterpreting their symptoms. Where some participants had not thought the symptoms indicated a serious condition, they lived with pain or a growth until symptoms failed to resolve, or worsened, leading them to seek help: *"I waited a little while before going to the doctors and we all noticed it was getting larger"* (P3, e-mail). Others delayed help-seeking seemingly through not wishing to engage with what their symptoms might indicate: "*I did bury my head in the sand quite a lot"* (P18, Phone).

After seeking help, several participants felt that a delay in diagnosis resulted from healthcare professionals' (HCPs) uncertainty: "*They couldn't be certain what it was initially*" (P8, e-mail). Others felt that they were referred for tests or specialist care that were inappropriate and would not detect DF:

> "*I was then referred to a[. . .] cancer clinic where I was told it was normal, that there was no lump and that it was just bone*" (P3, e-mail).

Table 1: Description of participants.

Age	22–59 years (median 35.5)
Ethnicity	*n*
White British	14
Others	4
Not stated	2
Location	*n*
Northern England	3
East/West Midlands	4
South East England	5
Others	4
Not stated	4
Tumour location	*n*
Abdominal wall/muscle	4
Leg/foot	6
Internal	3
Bone/joint	4
Neck/shoulder	3
Number of tumours	*n*
1	18
>1	2
Interview method	
Email	12
Phone	8

Thus, a lack of awareness of DF and its symptoms seemed to lead to delays in participants seeking healthcare, and then, an apparent lack of knowledge of some HCPs seemed to further contribute to delays in DF diagnosis.

Diagnostic delay seemed to enhance individuals' worry, especially if they believed a lump could be cancerous: "They thought it might have been sarcoma, that ruined my life for a few months" (P7, e-mail).

Uncertainty seemed to continue after diagnosis, with participants feeling it was unclear which treatment would be best for them:

> *"I wish the doctor had gone "I'm putting you on this" whereas "do you wanna go on this or this" and I don't have the knowledge as to [. . .] which treatment works for me" (P15, phone).*

It seems that some struggled with being in a position where they had a role in choosing a treatment, feeling uncertain as to whether they were selecting the best option.

3.2.2. Healthcare Experiences. Reported healthcare experiences varied. Some participants reported receiving support and understanding from staff; others perceived staff to be unfriendly or dismissive of their difficulties.

The perception of being dismissed by HCPs was raised by several participants, across stages of the healthcare pathway, from the first GP visit to receiving treatment. For example, one felt dismissed by their GP on presenting with pain:

> "*I went along to my GP and showed him [the lump], his attitude was "well yes I can feel something there but as*

you've got pain it's not cancer, it's nothing to worry about"" (*P17, Phone*).

For this participant, the sense of being dismissed seems to have been reinforced by their perception of their first contact with a consultant: "*the first consultant that I saw there, that again was his attitude, "oh you've got pain so it's not going to be anything serious*"". The consultant may have intended to be reassuring, ruling out cancer, but the participants seemed to feel that they were not being taken seriously.

The belief that some people view DF as less serious than cancer seemed to contribute to participants' feeling dismissed: "*some may dismiss me as DF in their eyes is not a serious condition*" (P1, e-mail). Other participants reported that it was their worries around treatment that was dismissed by HCPs:

"I felt like I was being stupid, they made me feel like I was being well, why are, you know why are you so upset? Why are you so *scared?"* (P20, Phone).

This participant was feeling anxious when receiving chemotherapy and did not seem to experience the support that they felt they needed.

Some participants seemed to perceive HCPs as cold or unfriendly, especially in cancer wards where some received treatment. One participant who was anxious seemed to feel that a staff member exacerbated their anxiety rather than providing understanding and support:

"My care at a cancer clinic was horrendous. [. . .] I received an extremely frosty reception from the doctor. [. . .] She spoke down to me and made me feel extremely small" (P3, e-mail).

Another participant who perceived staff to be unfriendly seemed to attribute the apparent lack of empathy to the fact that hospital procedures were normalised, daily experiences for staff, such that they may not appreciate the impact of processes on patients:

"I didn't find my chemotherapy experience very good [and later] I found them very cold and very erm what's the word I can use, just I know it's their job and I know they deal with it every day but you know each person I believe is individual" (P20, Phone).

This participant felt that the lack of empathy they perceived contributed to heightened anxiety and influenced their decision to discontinue chemotherapy:

"I think that's again contributed with other reasons why I didn't go ahead with more chemotherapy" (P20, Phone).

Some participants reported receiving excellent support from hospital staff:

"all the healthcare has been really good and through all this I cannot fault them I mean [the hospital] has been absolutely amazing the whole time, really supportive" (P15, Phone).

However, others seemed to feel support was lacking:

"they're literally just telling me my scan results and just generally asking how I am and "off you pop" sort of thing, I don't feel there's any kind of support [. . .] there's been no offer of support groups or, I've had to seek them out myself [. . .] so, more support would be good. Massively" (P20, Phone).

Some participants appeared to perceive support to vary across hospitals. P11 (e-mail) "*felt unsupported*" in general hospitals but felt support at a specialist cancer hospital "*has been great.*" One participant who was treated at a site with both a sarcoma team and a specialist DF team expressed a strong preference for care with the specialist DF team. Experiences across hospital types were variable, such that individuals reported positive, as well as negative experiences in nonspecialist settings:

"I noticed that some sarcoma clinics are better than others, and consultants have varying levels of awareness, knowledge and even interest in the condition" (P9, e-mail).

Overall, experiences with healthcare differed, with some individuals feeling well supported, but others feeling dismissed and unsupported by HCPs. It is unclear whether these findings are related to individual differences in patient needs and HCP practice or whether there are cultural differences across hospitals or care teams.

3.2.3. Comparisons to Cancer. Comparisons between DF and cancer were commonly discussed; the analogous diagnostic and treatment pathways of DF and cancer, with some individuals treated on the same wards as people with cancer, perhaps made such comparisons salient. Some participants appeared to view their diagnosis positively compared with a cancer diagnosis and seemed to find such comparison beneficial:

"Which I guess helps with my, the mental side of it because I know that it's just an inconvenient lump rather than actually like, it could have been a big ugly deadly cancer and it is not so thank God for that" (P19, Phone).

Many participants reported receiving an initial cancer diagnosis prior to learning they had DF. This may have led to this sense of relief, with DF appearing less serious in comparison, even if individuals were uncertain of the implications of a DF diagnosis:

"He [oncologist] phoned me himself and said, "I wanted to phone you and tell you that it is a fibromatosis and it is a benign tumour" and I went "oh' I was just, I was relieved, I didn't know what that meant, you know, I didn't know if there was anything that could be done at that stage" (P20, Phone).

However, other participants seemed to feel a cancer diagnosis would have preferable aspects because it would then have a clear clinical pathway:

> *"[the consultant] was like "actually if it was cancer, we'd have a set treatment plan we'd know what to do, but with this we don't really know what to do and it's more of a case of just seeing what happens on each of these treatment plans because things work for some people, things don't work for other people"" (P15, Phone).*

Furthermore, some participants noted that they were not offered the same treatments as cancer patients: "*you are told it's not cancer so it's not worth the risk with the treatments*" (P11, e-mail). It may be that some individuals' perceptions of the seriousness of the condition, and willingness to take risks with treatments, may differ from clinicians' views. In contrast, other participants found the analogous treatment pathways of DF and cancer to be distressing, as some treatments are widely associated with cancer: "*It [chemotherapy] heightened my anxiety, because you know I just associate it with cancer*" (P20, Phone).

Several participants compared DF with cancer when considering the outcome. Some were relieved that they did not have cancer; others seemed disappointed as, unlike some cancers, there was no cure:

> *"sometimes I think a desmoid tumour can be worse than cancer because there's no specific cure for it, because they actually grow back" (P14, Phone).*

Some participants seemed to feel their needs were less important than those of cancer patients, whom they deemed to be in a worse situation: "*guilty for moaning when there are people out there with cancer*" (P3, e-mail). It seems that the comparison of DF with cancer may make it difficult for some individuals to see themselves as worthy of care and support. There was also a sense that friends and family were dismissive of DF, considering cancer to be more serious:

> *"you say it's not [malignant], it's benign and they're like "well what are you complaining about then?"" (P15, Phone).*

Some participants seemed to feel that HCPs shared the perspective that DF is less serious than cancer and that people with DF merited less support than cancer patients:

> *"it does feel like there's two very* distinct*, you know, this is how you get treated if you've got cancer, and if you are unlucky enough to get the desmoid, then you're just, that's it, you're not treated the same"* (P18, Phone).

Overall, it appears that the alignment of DF and cancer in terms of symptomatology and clinical management may lead to comparisons. Such comparisons can not only be beneficial but can also contribute to anxiety and feelings of inferiority.

3.2.4. Psychosocial Impact. DF had a marked impact on some participants' emotional well-being: "*The emotional turmoil of DF affects you just as much as the physical side*" (P3, e-mail). Low mood and anxiety were commonly mentioned by participants. The main reason for low mood appeared to be chronic pain; P2 (e-mail) seemed to feel like giving up on life due to their pain increasing "*as like most days I don't want to continue with it as I've had enough of the pain*." Mood changes caused by pain seemed to impact social relationships:

> *"it [DF pain] can make me very irritable and tense" (P1, e-mail); "I am then short tempered sometimes with my family" (P10, e-mail).*

Many participants mentioned some degree of DF-related worry. For some, worries seemed to focus on the knowledge that their tumour may reoccur or grow. Individuals reported being hypersensitive to changes, in case they signified recurrence:

> "*Every pain I feel in that area I wonder if it's growing back [. . .] I am constantly worried or overthinking the situation"* (P3, e-mail).

A key reason for worrying about growth appeared to be fear of increasing problems. Several participants felt they were coping with their current situation but feared they could not cope if their condition worsened:

> *"It is always a worry what would* happen *if it got worse or if other tumour sites popped up"* (P10, e-mail); *"I'm worried it might turn into something a wee bit more scary"* (P4, Phone).

It seemed that DF could also impact on psychosocial well-being by creating a sense of isolation. Some participants felt that others could not relate to their experiences: "*alone and feel no one understands what you're going through"* (P3, e-mail). Support groups seemed to help negate feelings of isolation: *"this group really helped me to not feel alone anymore"* (P3, e-mail). Other participants who experienced isolation related this to mobility limitations which made it harder to meet friends and partake in social activities:

> *"my social life has been affected as I cannot join several activities (sports, clubbing; eating is sometimes challenging)" (P9, e-mail).*

4. Discussion

People with DF experience many difficulties related to diagnosis, healthcare, and living with DF according to the results of this study. Most participants reported a delay in receiving a DF diagnosis. Some found the uncertainty surrounding treatment pathways challenging. Many participants felt they lacked support and understanding from HCPs, although positive experiences were also captured, with some participants reporting good support and understanding from

HCPs. The analogous diagnostic and treatment pathways of DF and cancer seemed related to distress for some. Following DF diagnosis, comparisons to cancer seemed largely unhelpful, with some participants feeling inferior to people with cancer. However, some participants appeared to be relieved not to have cancer. Most participants mentioned the negative psychosocial impact of DF.

Diagnostic delay is common in rare conditions due to lack of awareness outside of specialist teams [18]. Patients are less likely to recognise rare conditions and seek help [19]. Delay may also arise after seeking help from HCPs as presentations of DF differ between individuals making diagnosis difficult [20].

It is unclear why some participants perceived lack of empathy or understanding from HCPs. Some HCPs may be unaware of the difficulties people with DF experience. However, this issue requires further investigation. It would be helpful to understand the perspectives and experiences of HCPs. The present study also identified that comparisons with cancer patients could cause individuals with DF to see themselves as less worthy of care and to perceive that others view their condition as less serious. Individuals with DF have different needs from people with cancer [3]. Gronchi et al. [21] suggest that DF patients should be treated by professionals who specialise in DF, as they are more likely to understand and validate the difficulties patients face. Husson et al. [3] similarly advocate for care in specialist centres.

Negative psychosocial impact of DF was clear for participants. Previous research has linked some of the psychological impacts to fears of potential regrowth [3]. Chronic pain is a common symptom of DF, and there is good evidence of a connection between chronic pain and depressive moods [22]. Psychological support has been deemed necessary following DF diagnosis [23].

5. Strengths and Limitations

Using phone and email interviews allowed participants from across the UK to participate. This facilitated the capturing of experiences from a variety of hospital sites which is important as care seemed to vary between hospitals. There are additional potential benefits to using email interviews. Participants may be more comfortable discussing sensitive or personal topics via email [24]. Email interviews do not require involvement at a fixed time, enabling individuals with other commitments to participate. Email interviews allow participants to fully reflect upon experiences before answering, leading to well-thought-out responses [25]. In the present study, the email responses obtained were well articulated, personal, and focused on the interview schedule, with one participant noting the therapeutic quality of writing about her experiences. Both phone and email data collection methods enabled the collection of rich data.

Whilst being able to capture experiences across a variety of sites, for individuals treated in both specialist and nonspecialist settings, the design of the present study was not suitable to systematically examine and compare experiences across treatment settings. It would be valuable for future research to address this issue.

Only one male took part. More females than males are diagnosed with DF (ratio 2 : 1, [26]) so it is likely that more women than men would use the groups we recruited from and volunteer to take part in the study. No participant mentioned gender impacting on their experiences, and experiences shared by the male participant did not appear to markedly differ from other participants. However, previous research has found some gender differences, for example, diagnostic delay in cancer was found to distress women more than men [27]. Also, Husson et al. [3] found male participants expressed concerns about disease growth or recurrence more often than female participants. It would, therefore, be beneficial for future research to ensure men's experiences are represented.

Recruiting from support groups may have resulted in the recruitment of individuals who feel that they need support with DF. People who feel they are coping well and who already feel well supported may be less likely to engage with these support groups. Nevertheless, it is perhaps particularly important to capture the experiences of individuals who are struggling most with the condition.

5.1. Clinical Implications. Greater awareness of DF in GPs and nonspecialists may help to reduce diagnostic delays. Treating people with DF in specialist wards could be beneficial. DF is a different condition to cancer and reacts differently to some treatments, and patients may benefit from its being treated as a unique condition. This might help patients to feel more supported and more confident in HCPs, and it could also reduce comparisons with cancer. DF has an unpredictable clinical course, with uncertainty regarding the best treatment options, and individuals may require greater support when making treatment decisions. Individuals may also benefit from psychological support when managing their condition and chronic pain.

6. Conclusion

Participants reported delays in diagnosis, uncertainties around treatment decisions, negative impact of DF on psychosocial well-being, and a need for support. Improved awareness and understanding of DF by health professionals may benefit patients at all stages of the treatment pathway. People with DF may also gain from being treated by specialist DF teams, separately from people with cancer.

Appendix

A. Interview Schedule

First, we are going to start with some open and general questions about your experiences with DF:

(1) Experiences of DF

  (a) To start off, can you tell me about your experiences of living with DF?
  (b) How does this condition impact your everyday life? (for example, how does DF affect what

you're able to do? How has your life changed since DF?)
(c) Would you be able to tell me how you first found out you had DF? (e.g., did you notice a lump?)
(d) Please can you describe any symptoms you have?

(2) The next few questions are about your experiences with healthcare
(a) So firstly, can you tell me about your experiences with healthcare? (for example, experience of diagnosis/treatment, experiences with your GP/hospital care?)
(b) What did you think about information you received from healthcare staff about your DF or DF in general?
(c) Could you tell me more about treatment options you were offered?
(d) Can you tell me more about any treatments you have received?
(e) Could you tell me about your experience with treatment _____
(f) In what ways have the treatments helped?
(g) Did you suffer from any side effects/negatives of treatment?
If watch and wait:
(h) How did you find watch and wait?
(i) In what ways did you find watch and wait helpful?
(j) Were there any negative aspects of watch and wait?
(k) Do you understand why you were offered watch and wait?
(l) What aspects of the care you received have been helpful? Were any aspects unhelpful?
(m) How do you think the healthcare you received could be improved?

(3) The next three questions are designed to capture your thoughts about DF
(a) How long do you think you'll have DF for?
(b) What do you think caused your Desmoid tumour?
(c) What consequences do you associate with having DF? (likely already answered)

Thank you very much . . . . The final questions are simple fact-gathering questions, so firstly,

(1) Please could you tell me your age?
(2) What is your gender?
(3) What is your ethnicity?
(4) How long have you had DF for?
(5) How many tumours do you have?
(6) Where are they location on your body?/where is it located on your body?

Is there anything else that I have not raised that you feel is important or would like to discuss?

Data Availability

The data are not currently available outside of the immediate research team, in line with our ethical approval.

Disclosure

The findings and conclusions conveyed in this paper are those of the authors and not of Desmoid United UK nor Sarcoma UK. This research project was conducted as part of an unfunded MSc Research project at the University of Manchester.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

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