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**Patient's perspectives of living with a precancerous condition: monoclonal
gammopathy of undetermined significance (MGUS)**

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1 Figure

Abstract:

Purpose:

The aim of this study was to investigate patient experiences of living with monoclonal gammopathy of undermined significance (MGUS). Living with a premalignant condition such as MGUS may elicit negative psychosocial effects including increased anxiety and fear of progression to cancer. To date, no study utilising qualitative methodology has explored the lived experiences of MGUS patients.

Methods:

Data was collected via two focus groups and six telephone interviews. MGUS patients (n=14) were recruited via nurse-led hematology telephone-clinics in Northern Ireland. Interviews were transcribed verbatim and the data subjected to thematic analysis.

Outcome:

Thematic analysis identified 3 overarching themes; (1) The psychosocial impact of an MGUS diagnosis, (2) Knowledge of MGUS and (3) Experiences of MGUS health services. Patients with MGUS reported experiencing poor psychological adjustment to their condition particularly at the point of diagnosis and approaching follow-up appointments. Feelings of isolation, poor information-provision, increased uncertainty and limited psychosocial support for MGUS patients were also reported. Patients did however reflect positively on their experience of being followed up via nurse-led telephone clinics.

Conclusions:

Provision of patient friendly information guides at diagnosis, and additional psychosocial support services such as nurse-led telephone clinics and coordinated patient groups may help MGUS patients adjust better to their diagnosis and in doing so improve quality of life in this patient population.

Key words:

Monoclonal gammopathy of undetermined significance (MGUS), multiple myeloma, Quality of life, Qualitative, Precancer.

Introduction

Monoclonal gammopathy of undetermined significance (MGUS) is an asymptomatic premalignant blood disorder which precedes multiple myeloma (MM), an incurable B-cell malignancy (Kyle et al., 2006). The annual rate of progression to MM and related lymphoproliferative disorders such as Waldenström's macroglobulinemia, and lymphoma has been reported to be 1% (Kyle et al., 2002), meaning the vast majority of individuals diagnosed with MGUS will not progress to MM. MGUS is more common in males (Wadhera and Rajkumar, 2010), and individuals of black ethnicity (Landgren et al., 2007, 2006). Younger age at diagnosis has been reported among black individuals (median age of diagnosis: 66 vs 70 years old (white individuals) (Landgren et al., 2017). MGUS prevalence is estimated to be 3.2% in adults over 50 years old, however, most individuals remain undiagnosed due to the asymptomatic nature of presentation (Kyle et al., 2006; Therneau et al., 2012).

MGUS patients often experience considerable hospital activity pre- and post-diagnosis, implying diagnosed cases are living with comorbidities (Lamb et al., 2019). MGUS is typically detected incidentally during investigations for other conditions, with an elevated total protein level leads to serum protein electrophoresis (SPE) which detects a paraprotein (International Myeloma Working Group, 2003; Kyle et al., 2010). Individuals are diagnosed when a reduction of one or more immunoglobulin class (IgG, IgA and IgM) levels are detected from a serum protein electrophoresis (SERP) test (Bird et al., 2009). The International Myeloma Working Group (IMWG) defines the parameters of MGUS as having a serum M protein <30g/l, <10% clonal plasma cells (PCs) in the bone marrow and, most importantly, the absence of end-organ damage that can be attributed to the PC proliferative disorder or other B-cell proliferative disorders (International Myeloma Working Group, 2003; Kyle et al., 2010). Once diagnosed, it is recommended that MGUS patients are followed-up regularly (every 3-12 months) to identify early signs of progression to MM (Bird et al., 2009; Smith et al., 2007). Within the UK, this is often conducted by clinical nurse specialists (CNS) utilising telephone clinics for low-risk patients; under the guidance of haematology consultants (Rawstron et al., 2007).

Studies investigating the quality of life of patients with haematological precancerous conditions is limited. Recent quantitative cross-sectional research on MGUS and smouldering multiple myeloma (another higher risk MM precursor) has indicated that these patients exhibit similar psychological distress and mental health-related quality of life (HRQoL) as patients with active MM (cancer) (Maatouk et al., 2019). Compared to MM, MGUS is considered to be asymptomatic with the literature suggesting minimal physical impact (Kyle et al., 2011). Similar qualitative studies of other precancerous conditions, such as Barrett's oesophagus, identified a lack of social support, poor information provision and negative psychological reactions, e.g.

increased anxiety, as central concepts of living with a diagnosis of a premalignant condition (Kennedy et al., 2012; Lee Mortensen and Adeler, 2010). This study aimed to illustrate the experiences of receiving and living with a MGUS diagnosis.

Methods

Design

This study was a qualitative design, which utilised an integration of focus groups and telephone interviews to collect and integrate the data. The Consolidated Criteria for Reporting Qualitative Studies (COREQ) (Tong, Sainsbury, & Craig, 2007) guided the reporting of the study. Participants were identified using convenience sampling and recruited during their routine telephone surveillance appointment by CNS' at two Healthcare trusts (Belfast and Southern) in Northern Ireland. During these appointments the CNS discusses patient's blood test results and assesses their general health; with a goal of identifying potential signs of progression such as increased infections, bone pain and/or fractures (Rawstron et al., 2007). All patients on telephone follow-up were considered low risk for progression.

Prior to invitation, the CNS assessed each patient against eligibility criteria. Individuals were not eligible if they were considered to be too frail or had neurocognitive difficulties or severe mental health issues which could affect their ability to provide consent. The CNS introduced the study to participants during their routine telephone appointment. Interested patients were mailed a study information pack (containing a study information booklet, a consent sheet, a contact information sheet, a pen and a prepaid envelope to return the consent and contact information forms) by the CNS. Suitable times for the focus group/interview were then organised by the university-based study team by telephone call. Non-responders received a reminder telephone call from the CNS after two weeks. No patient had a prior relationship with the research team; the latter was separate to the clinical team involved in recruitment. Prior to recruitment, study documentation was reviewed by a subset of (non-MGUS) patients in the Northern Ireland Clinical Trials Centre 'Personal and Public Involvement in Research' committee.

Both the interviews/focus groups followed a semi-structured schedule (Appendix 1) developed by the study team in consultation with the published literature. Data was collected via two focus groups and six telephone interviews with MGUS patients aged 40-70 years old in 2015-16. Poor focus group recruitment led to incorporating telephone interviews to increase numbers and provide a wider range of opinions and individuals (Stokes and Bergin, 2006). Patients were offered the choice with all preferring the interviews. This multi-method monostrand design (combining focus

groups and interviews) a more holistic approach to the data richness (Barbour, 2014). A critical review endorsed this integration of the methods as it *"leads to an enhanced description of the phenomenon's structure and its essential characteristics"* (Stokes and Bergin, 2006).

Focus groups were led by an experienced qualitative researcher (OS or CT; both female with expertise outside MGUS field) while two other study team members (CMcS and BB; both female with expertise in the area) attended to take notes and assist with logistics. Focus groups took place within a non-clinical setting and lasted approximately one and a half hours. Telephone interviews lasted approximately 30 minutes and were conducted by BM (male with MGUS research expertise). Focus groups and interviews were recorded on a digital voice recorder, transcribed verbatim, and rechecked against the recordings and relevant field notes. Recruitment was carried out until a point of saturation meaning that "sufficient data to account for all aspects of the phenomenon were obtained" (Morse et al., 2002). Draft transcripts (one-page extract) were sent to a subset of patients (n=7) for respondent validation.

Data analysis

Transcripts were analysed using inductive thematic analysis (Braun and Clarke, 2006) following the 6-step trustworthiness criteria (Nowell et al. (2017). As such, interviews were conducted and data were gathered, coded and analysed by at least two researchers independently and then these data rounds were discussed by the two researchers and presented to members of the wider interdisciplinary research team for further analytical discussion. The iterative rounds continued until there was agreement that no new data or no new themes emerged from the transcripts. The data was organised using NVIVO v11 (QSR International Pty Ltd, 2015). Theme development was similar between the data collection methods. Verbatim quotations were used to provide evidence for the researchers' interpretations.

Ethics considerations

Ethical approval was obtained from the Office for Research Ethics Committee Northern Ireland (Ref: 13/NI/0073). Informed consent was obtained from all study participants. A distress protocol was in place due to the potential for participants to become distressed while recalling their lived experiences. At the end of the focus group/telephone interview, participants were provided with an information pack via post; containing an information leaflet and contact details for charitable agencies (example, Myeloma UK\Bloodwise) for additional information or support if interested.

Results

In total, 14 individuals participated in this study: n=8 focus group participants (focus group 1 n=6, focus group 2, n=2), and six participated in telephone interviews (TI 1-6). The participants were predominantly male (n=8/14), married (n=13/14) and educated to at least GCSE or O-level/high school standard (n=14) (Table 1). All patients were being followed-up for their MGUS diagnosis via nurse-led telephone clinic at 3-12 month intervals. Patients varied on time since diagnosis (from <1 year to >8 years). Six patients reported co-morbid long-term conditions (specific information on these conditions were not captured).

Thematic analysis identified 3 overarching themes; (1), The psychosocial impact of an MGUS diagnosis, (2) Knowledge of MGUS and (3) Experiences of MGUS health services, Figure 1.

Table 1 Demographic characteristics of the patients

Table 2 Sociodemographic factors of individual patients

Figure 1. Coding tree for themes and subthemes.

1 The psychosocial impact of an MGUS diagnosis

2 The first major theme identified was the psychosocial challenges of an MGUS
3 diagnosis and how this fluctuated across the MGUS pathway. In particular, patients
4 discussed heightened emotions at diagnosis, including shock and fear. Interaction
5 with cancer services also invoked social comparisons with cancer patients and
6 increased fears of progression.

7
8 Patients described their diagnosis as "*the shock of my life*" (**TI.2**), with some viewing
9 their diagnosis as an existential threat to their future. Patients reported completing
10 wills and purchasing cemetery plots. These patients wanted more information and
11 appeared to have been more anxious at diagnosis than other participants. However,
12 all patients were aware of the potential for progression to cancer and reported some
13 initial anxiety relating to this.

14 *"To realise that this had the potential to be cancerous was a shock and it certainly*
15 *made me think about my mortality which I had-...obviously had thought about*
16 *before but I thought about it even more and I did make a will and I did buy a grave*
17 *(laughing). Basically I thought "Right I better start getting organized, just in case this*
18 *leads to something awfully terrible". **TI.2***

19 For many patients, the shock developed into anxiety post-diagnosis; with patients
20 describing consistent thoughts about their mortality during this time. The impact of
21 the diagnosis and hearing the term 'cancer' led to some missing important MGUS
22 information during the initial consultation. This shock and anxiety was present until
23 their follow-up appointment, usually 3 months' post-diagnosis; when patients could
24 ask questions and process the information better.

25
26 The psychosocial impact seemed to reduce over time; as patients came to terms with
27 their condition. Most patients had lived with MGUS for many years and their worries
28 about the consequences lessened over time. Their fear of progression to cancer was
29 compared to "*Damocles sword*" (**FG2.2**); a consistent but mainly dormant fear. Their
30 fear that their next appointment could be *the* appointment they received bad news
31 from the CNS and had progressed to cancer.

32 *"I think it's sort of a Damocles, hanging very high-- you know, it sort of-- not likely--*
33 *Sort of a high percentage chance of not developing anything". **FG2.2***

34
35 For some patients, MGUS was a spur to improve their lives and make lifestyle
36 changes, with patients reporting increased physical activity and improving their diet
37 to lessen their risk of progression.

1 *"I'm trying to do a bit of running. So it maybe gave me a little bit a kick in the*
 2 *backside to go out and do something, lose a bit weight. It's-- it was good that way.*
 3 *Was it because of that? Yeah, but that was only maybe more in the mind to, you*
 4 *know, I've got to do something to look after. I thought I was going to die from a*
 5 *heart [condition] rather than of MGUS". FG2.2*

6
 7 MGUS was often overshadowed by medical issues of friends/family, especially if
 8 cancer-related. Patients felt that their MGUS diagnosis was less important and tried
 9 to avoid causing worry and anxiety by not talking about their MGUS diagnosis. As a
 10 result, some patients felt isolated with their diagnosis; having no-one to speak to
 11 about their worries. Male participants were particularly reluctant to speak about their
 12 MGUS diagnosis due to their lack of understanding about the condition and burden
 13 this may place on their families/friends. The asymptomatic nature led to some
 14 patients comparing it to a mental health diagnosis; where patients were healthy on
 15 the outside but unwell inside.

16 *"Cause it's asymptomatic, so there are no symptoms associated with MGUS. It's*
 17 *seems to be that it's a hidden illness. So that may be one of the reasons why people*
 18 *don't really know much about it." FG2.2*

20 **Patient's knowledge of MGUS**

21 The second major theme identified was how patient's knowledge of MGUS affected
 22 the MGUS experience; particularly around acquiring knowledge from HCPs and the
 23 Internet. While some patient-friendly information helped patients to be more
 24 confident about their diagnosis and take an active role in their own care, poor
 25 information led to decreased psychosocial wellbeing.

26
 27 Patients found the full name (monoclonal gammopathy of undetermined
 28 significance) difficult to understand, remember and explain to others; such as family
 29 and friends. Confusion was heightened by the differing terminology used by HCPs
 30 when they were trying to explain the condition to patients. Patients reported that
 31 MGUS was described to them by HCPs as a; "*protein deficiency*" (FG1.4), "*raised*
 32 *protein*" (TI.4)", "*benign blood abnormality*" (TI.2) and a "*rogue blood in my system*"
 33 (TI.3). Many felt this was a contributing factor to their confusion and anxiety at
 34 diagnosis.

35 *"What does the word (MGUS)-- what does the 4 letters mean?" FG1.2*

36 *"Monoclonal gammopathy of undermined significance." Interviewer:*

37 *"And that's why nobody can remember it." FG1.2*

1

2 There were significant differences in patient's actual and desired level of knowledge.
 3 Some patients reported wanting to "live in a bubble" (**FG1.3**) and did not wish to
 4 know anything beyond the essential information; such as when their appointments
 5 were. On the other hand, other patients kept detailed records of their blood scores
 6 (e.g. free-kappa-lambda ratio). For these patients, feeling informed created a sense
 7 of empowerment through feeling that they were an active participant of their care.
 8 These patients were able to describe the link between MGUS and MM and lymphoma
 9 and define the progression risk to MM "1% per annum" (**TI.4**). Other patients
 10 reported their knowledge as low to medium and many desired to improve their
 11 knowledge.

12

13 Patients who did not receive information leaflets at diagnosis reported more
 14 extensive online knowledge seeking than those who did. Patients described their
 15 experiences of searching for MGUS information online as challenging and websites
 16 difficult to navigate; with most of the information using unfamiliar and complex
 17 language or referring to information in other countries (especially the USA). As a
 18 result, many patients were linked/directed to MM (not MGUS) information, which
 19 caused significant anxiety and worry particularly if identified shortly after diagnosis.
 20 Patients illustrated how they found negative and fear-inducing stories when
 21 searching online at diagnosis; as they lacked the understanding to differentiate
 22 MGUS and MM information.

23 *"I sort of looked up what MGUS was .I looked up online and I sort of had a fair idea*
 24 *what it was well sort of an idea what it was so I was probably a wee bit apprehensive*
 25 *because I thought it's possible-...I could not have cancer but I could possibly be*
 26 *getting cancer so I did feel a bit (shocked) ". TI.2*

27

28 Patients interacted with HCPs in order to gain information in relation to MGUS to
 29 educate and empower themselves. Patients sought information from three types of
 30 HCP; their haematology team (doctors and clinical nurse specialists), their GP and
 31 personal contacts within healthcare who were HCPs.

32

33 Patients described how receiving good communication from their haematology team
 34 at diagnosis facilitated less anxiety and greater understanding. Good communication
 35 was described as the HCP taking the time to explain the condition and providing
 36 written materials at diagnosis.

37 *"No information sheet, nothing. You were just kind of sent away. And I actually had*
 38 *to try and remember what it was, because as everybody knows, when you're in with a*

1 *medical professional you probably retain about a quarter of what they said. So I*
 2 *came way, and the only thing I remembered was Mono. And I thought, "What was*
 3 *that? What was the rest of that?" And I was trying to remember, cause that was it."*

4 **FG1.5**

5
 6 Patients described how GPs were important providers of information, where they had
 7 their blood tests and general healthcare but generally reported poor MGUS-specific
 8 knowledge. Patients reported they often felt more knowledgeable than their GP
 9 about MGUS. Patients who reported that their GPs were knowledgeable about MGUS
 10 appeared to better understand their diagnosis and felt reassured that they were
 11 receiving the best care possible. Patients were aware that GPs (and HCPs in general)
 12 have limited time available to inform themselves about all conditions, especially
 13 uncommon conditions like MGUS; but felt less anxious when their GP was
 14 knowledgeable. Patients wanted more GP-related resources to help GPs and
 15 patients, however, there was little indication as to what form these resources could
 16 take.

17 *"So after the information, what I was told, it sinks in. and you do hear things like*
 18 *"you should be ok" [Laugh] Um, but when it sinks in, your first port of call, beyond*
 19 *the internet, is the GP. So I placed a call to the GP, and said to me "I don't know. I've*
 20 *never heard of this".* **FG1.5**

21 *"My doctor (GP) was on top of it the whole time like my doctor's been really good,*
 22 *and she has, she was she keeps me informed of everything that's happening and she*
 23 *explains everything she's my doctor. She's one of the only doctors that speaks my*
 24 *language if you know what I mean. I have all the confidence of the day in her cause*
 25 *she'll always go over the, the extra to help you."* **TI.1**

26
 27 Patients whose relatives/friends were qualified health care professionals (such as
 28 doctors, nurses and pharmacists) reported improved knowledge and understanding
 29 of their condition post-diagnosis. Patients whose partners were healthcare staff
 30 described how they prepared questions for their appointments.

31 *"My wife (a nurse) had lists of questions, that she wanted me to ask. Now, and every*
 32 *time (Nurse Specialist) phones me now, I have those lists of questions now.* **FG1.6**

34 **Experiences of MGUS related health services**

35 The final theme describes how patients were referred to MGUS health services and
 36 their experiences of health services and staff since diagnosis. Participants recalled
 37 different challenges and experiences, depending on the part of the patient pathway

(pre-diagnosis, immediately post- diagnosis or a long-term MGUS patient) being discussed.

Most patients described being diagnosed incidentally when being investigated for non-related medical issues, such as high blood pressure, co-morbidity appointments (e.g. asthma), hospitalisation for acute illness (e.g. pneumonia) and acute injuries (e.g. knee trauma). Typically, elevated paraprotein was initially investigated in the haematology department, which interviewees said was located within the “cancer centre”, which generated fear and anxiety for some patients.

In one case, a patient previously under investigation for MM was relieved to have been diagnosed with MGUS; as they were not a “*cancer patient*” (**FG1.1**). Therefore, their experience of entering the MGUS health services was more positive than many of the other participants.

“I have to say this, because this (location of haematology) really irked me, and I think it was because it was done over in (Local Hospital’s Cancer Centre). That very place. God bless everyone”.

FG1.3

All patients were under surveillance via a telephone clinic and are informed of the results of their surveillance-mandated blood tests by the haematology clinical nurse specialists. This typically includes a discussion of the blood result scores, inquiries about the patient’s general health and an opportunity for patient questions. Some patients kept a record of their blood results at each appointment. Patients were overwhelmingly satisfied with telephone surveillance, with none discussing negative experiences.

The telephone clinic offered an alternative to hospital-based consultant-led appointments by offering collaborative management between the haematology clinic and their primary care physician. The telephone clinic was reported to be more convenient and was especially beneficial for rural patients, for whom visiting the hospital and consultant in another town/city was seen as burdensome and time-consuming. Patients also reported that telephone follow-up helped to reduce anxiety as they were able to avoid seeing cancer patients at the cancer centre (a reminder of what their diagnosis could progress to). Patients perceived the telephone clinic reduced burden on secondary care services (haematology staff especially doctors/consultants) and were supportive of improvements made to the service.

“I think that -- that telephone follow up is --is a Godsend.” **FG1.6**

1 *"The telephone clinic I think to me that's probably really all I need it would seem, it*
 2 *would seem to me you know an awful waste of time to come down and taking up*
 3 *the doctor's time in the hospital or anything I mean this is only a... quick telephone*
 4 *conversation". T1.4*

5 *"Well, whenever I have the telephone appointment with the nurse I feel there's a*
 6 *little bit-... I'm wondering what I'm going to be told am I getting worse or is my*
 7 *health deteriorating. So I'd be glad whenever the conversation's finished." FG2.1*

8
 9 Despite an overall sense of satisfaction, most patients worried about the telephone
 10 clinic but realised that it was necessary. The waiting period between testing and
 11 results, which can be weeks, was highlighted as challenging. Patients reported
 12 anxiety during this waiting period and wondered if the blood tests would reveal an
 13 increase in disease markers and/or reveal progression to cancer (MM).

14
 15 Patients encountered a range of communication styles from healthcare professionals
 16 when being diagnosed and when they sought MGUS information. The style of
 17 communication mediated their experience of the health service and overall
 18 satisfaction. Some patients reported excellent psychosocial care, with clinicians
 19 (specialists and primary care physicians) taking time to explain the MGUS diagnosis,
 20 which led to less diagnosis-related anxiety with patients reporting that they felt
 21 informed and supported. Haematology nursing staff were seen as having a positive
 22 communication style. Nurses provided reassurance, reduced anxiety and provided
 23 "peace of mind" through their psychosocial care, provision and explanation of
 24 information. Participants reported feeling more comfortable speaking with nurse
 25 specialists than doctors.

26
 27 Other patients reported fewer positive interactions with doctors and recalled how
 28 these negative experiences were linked to feelings of isolation and uncertainty about
 29 their diagnosis, especially immediately post-diagnosis. Some patient's reported
 30 doctors in haematology not taking the time to describe their condition and being
 31 detached and dismissive of MGUS patients. While patients understood that other
 32 patients (especially cancer patients) required more care, they were disappointed at
 33 the lack of psychosocial care and empathy; with no/limited signposting to other
 34 information or being able to talk to someone about their diagnosis. This resulted in
 35 some patients having increased anxiety and feeling less informed.

36 *"Classic consultant. They go in and out of that every day, and they don't see it. They*
 37 *see people a lot worse than you. And they're just delivering a line, to say, "Away you*

1 *go". And the next patient in after you has got six months to live, or year. So they're*
 2 *focusing on him or her, rightly so."* **FG1.5**

3
 4 Patients discussed a sense of isolation/uncertainty regarding their diagnosis, which
 5 many patients felt could be alleviated by providing support structures for meeting
 6 and interacting with other MGUS patients. MGUS patients are often not supported by
 7 cancer support charities or groups and can feel in "limbo" (**FG1.1**), both in cancer
 8 services and supportive structures such as the voluntary sector. Patients proposed
 9 developing two structures; in-person support groups (similar to cancer support
 10 groups) and volunteer peer support (local) contactable MGUS patients' post-
 11 diagnosis, for questions or concerns. Travel and low patient numbers were identified
 12 as threats to the long-term stability of in-person meet-ups. Focus group attendees
 13 (compared to telephone interviewees) were more positive about meetings/support
 14 groups. Some patients valued the availability of a contactable MGUS patient who
 15 they could speak to over a "coffee or glass of wine" **FG2.1**. Developing this indirect
 16 support may be useful addressing this unmet need.

17
 18 *"There's nothing (to help coping if individuals are struggling). you*
 19 *know, I just get through it, eventually. But it's not like I can lift the*
 20 *phone and ring (FG1.3). Lift the phone and ring (FG1.4), and say*
 21 *"How are you feeling today?" You know, "I'm feeling pretty (poor)".*
 22 *There's nothing out there, there's nobody out there. And that's*
 23 *because we're in limbo."* **FG1.1**

24 25 Discussion

26 This novel study highlights the potentially negative impact that receiving and living
 27 with a MGUS diagnosis can have on patients, particularly at the point of diagnosis
 28 and time of follow-up appointments. Although receiving an MGUS diagnosis rarely
 29 had a life-changing impact, it did cause patients to re-evaluate their lives and to
 30 question their mortality. Most patients had a poor level of understanding of MGUS.
 31 Patients highlighted some issues in current MGUS service provision, especially in
 32 relation to information provision, but were positive about active surveillance
 33 provided by the nurse-led telephone clinic. Information was a powerful tool for
 34 patients, with good information and communication giving rise to improved
 35 understanding and reduced anxiety. The lack of available support for patients and
 36 their unwillingness to talk about MGUS to their families and friends, due to their own
 37 poor knowledge about MGUS and to avoid causing others anxiety was an issue for
 38 some patients.

1

2 The emotional impact of MGUS was complex and nuanced to each individual. At the
 3 initial diagnosis, all patients reported experiencing shock at being diagnosed with an
 4 asymptomatic condition linked to cancer. This shock was similar to that reported for
 5 receiving positive results from population-level cancer screening (De Morgan et al.,
 6 2002; Prinjha et al., 2011), other premalignant conditions (Gough et al., 2003;
 7 Hounsgaard et al., 2007; Kennedy et al., 2008; Shylasree et al., 2008) and
 8 haematological malignancies (Swash et al., 2016). For many patients, this shock
 9 developed into anxiety and fear; the potential of developing cancer remained an
 10 active concern in the weeks and months following diagnosis. This is similar to the
 11 experiences of MM patients who reported having a sudden and shocking
 12 confrontation with their mortality, by a condition that they had never heard of
 13 (Hauksdóttir et al., 2017). This anxiety often regresses when chronic illness patients
 14 become accustomed to their diagnosis and the uncertainty is reduced (Mishel, 1999);
 15 similar to the experiences reported by the MGUS patients in this study. MGUS
 16 patients outlined the initial diagnosis period as having the highest psychosocial
 17 impact on their lives and an area where intervention could be implemented in the
 18 future. As most of the patients were several years' post-diagnosis, further research on
 19 newly diagnosed patients may provide greater insight into immediate impact of
 20 receiving a MGUS diagnosis.

21

22 Knowledge of MGUS was one of the strongest messages from the collective voice of
 23 the participants. Overall, patients had poor knowledge of MGUS at diagnosis. There
 24 was a clear distinction between the patients with MGUS knowledge and those with
 25 less knowledge. Those with more knowledge appeared to experience less anxiety
 26 and improved coping. In the wider MM literature, MM patients reported the initial
 27 gathering of information and developing knowledge as important to acquaint
 28 themselves with their condition and reduce their distress (Hauksdóttir et al., 2017).

29

30 Patients are often unable to absorb verbal information at diagnosis (Kessels, 2003).
 31 Anxiety and isolation can result if the information from HCPs is considered to be
 32 lacking, confusing, or inadequately explained (Prinjha et al., 2011). Many MGUS
 33 patients reported not receiving an information leaflet at diagnosis, one of the most
 34 frequent sources of healthcare information for patients (Kenny et al., 1998; Meredith
 35 et al., 1995). However, there may be a recall bias in not recounting receiving the
 36 information. However in our previous research, only 42% of haematologists provided
 37 information booklets at all diagnoses (McShane et al., 2017). Nevertheless, receiving
 38 an information leaflet was linked to a more positive post-diagnosis experience. While
 39 acknowledging their condition may be lower priority for their doctor's time

(compared to cancer patients), the need for more doctor-patient communication and psychosocial care for MGUS patients was highlighted. Online searching was described as difficult with patients reporting contradictory and confusing information about MGUS. This finding is not surprising as haematological malignancies have previously been reported as being among the least well understood malignancies by patients (Department of Health, 2012).

The telephone clinic was universally preferred to the hospital clinic by patients for reducing anxiety related to visiting the "*cancer place*", and convenience (time and travel reasons). The telephone clinics, where the participants were recruited, follow the outreach model as proposed by Rawstron et al. (2007). Our study adds to the growing literature of positive patient-reported experiences with telephone clinics (Rawstron et al., 2007) and suggests that CNS-led clinics are a useful addition to MGUS service provision. The COVID-19 pandemic has increased tele-medicine/remote monitoring, which may accelerate development of MGUS telephone clinics nationally and internationally. Some patients felt their wait time between phlebotomy and receiving results was too long and extended their anxiety. It would therefore be useful for service providers, to consider mechanisms to reduce the length of this waiting period.

MGUS patients were often reluctant to share details of their diagnosis with others outside their immediate family circle, due to low awareness and the feeling that other's issues were more important; especially if cancer related. This was felt by some participants as obstructing their ability to cope with the diagnosis. Compared to the support available for cancer patients, MGUS patients felt peer support and support groups were lacking. Similar to other premalignant conditions (De Morgan et al., 2002; Dowswell et al., 2012; Kennedy et al., 2008), MGUS patients agreed that there was benefit in meeting other patients to discuss shared experiences. Patients attending the focus groups reported positive experiences in being able to see and talk (often for the first time) to others with MGUS. An official website featuring life stories and blogs was also advocated by patients. This style is in keeping with mainstream health websites including 'NHS Choices' in the United Kingdom and charity websites who aim to supplement scientific facts with experiential information (Kelly et al., 2013).

Clinical Implications

A number of clear considerations came from the patients in this study.

1. In line with the UK/Nordic guidelines (Bird et al., 2009), patient-friendly information and support is necessary at the point of diagnosis and thereafter for MGUS patients. Information booklets are available (e.g. Myeloma UK, Macmillan and the International Myeloma Foundation), however our results suggest these are not routinely provided at diagnosis. The information should be offered in various formats (verbal, paper and online) as patient needs differ. Information should advise on future follow-up procedures, disease progression and signs/symptoms to be aware of. Inclusion of 'life stories' of other MGUS patients in information leaflets was also suggested by patients who want to 'see' what other MGUS patients look like.
2. Many patients were diagnosed/followed-up initially in the local hematology department, however patients recalled this negatively as the '**cancer place**' owing to cancer patients receiving their treatments in the same department. Improving the clinical environment may reduce patient anxiety, improve knowledge absorption and reduce future psychosocial distress.
3. The use of telephone clinics was positively endorsed by MGUS patients in this study. Telephone clinics reduce patient burden by reducing hospital visits, which can incur both financial and psychosocial costs (Overend et al., 2008; Rawstron et al., 2007); the feasibility of expanding this service should be explored

Strengths and limitations

Our study is based on the lived experiences of 14 MGUS patients in two health and social care trusts in Northern Ireland. Our sample size is comparable to other premalignant studies which have reported on small sample sizes (under 16) (Hounsgaard et al., 2007; Kennedy et al., 2008; Lee Mortensen and Adeler, 2010; Likes et al., 2008; Prinjha et al., 2006; Pruitt et al., 2008). Despite a small sample data, However, despite this, we feel as a research team that this was an accurate representation of the views of NI MGUS patients but that there were further insights that could found with more participants in some sub-themes, which may have not reached data saturation.

When considering the transferability of our findings to the wider MGUS population, the younger age of participants (present study 55.9 vs 74 years old; Li et al., 2016), and low risk MGUS profile should be considered. Due to the small numbers and similar age range (predominantly 50-70 years old), we were unable to explore the impact of age on experiences. However, as patients diagnosed with MGUS at a younger age live longer with the knowledge of their condition and have an increased lifetime risk of developing MM; this younger group may receive a greater benefit from future interventions.

Combining the focus group and interview data has potential drawbacks. The increased interaction and sharing in the focus group led the data into different avenues which were not as dynamic in the dyadic interviews. These diversions provided greater insight of the lesser acknowledged and thought-of aspects of an MGUS diagnosis. Correspondingly, the in-depth nature of interviews and individual experiences provided finer details. Combining these modalities can cause disconnects between the experiences of focus group and interview participants and required the analysis to consider if the modality influenced this. However, we found the codes and themes were consistent during the analysis of both modalities. The use of the patient's CNSs as recruiters opens the possibility of recruitment bias, however this is a common recruitment mechanism in premalignant conditions (Kennedy et al., 2012; Pruitt et al., 2008). Information was not collected on those who did not indicate interest in participating

Conclusions

Life-long surveillance provides patients with a periodical reminder of their MGUS diagnosis and its potential progression to cancer, which can cause anxiety. Measures such as provision of information leaflets to all patients at diagnosis, patient support groups, improved HCP communication and diagnosis/follow-up within a non-cancer clinical environment may help improve health and psychosocial wellbeing of MGUS patients.

Conflicts of Interest and sources of Funding Statement

The authors have declared no conflict of interest exists. The corresponding author had full access to all the data and final responsibility for the decision to submit for publication. Funding for this study was provided by a Cancer Translational Research Group Young Investigator Grant. At the time of the study, Dr Charlene McShane was in receipt of a Cancer Research UK Population Sciences Research Fellowship.

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1 **Tables and Figures**

2 *Table 1 Demographic characteristics of the patients*

CHARACTERISTICS		NO. PATIENTS/ MEAN (%/RANGE)
GENDER		
	Male	8 (57)
	Female	6 (43)
AGE		
	41-50	2 (14.3)
	51-60	5 (35.7)
	61-70	6 (42.8)
	71-80	1 (7.2)
MARITAL STATUS		
	Married	13 (92.8)
	Divorced	1 (7.2)
LEVEL OF EDUCATION		
	Finished Secondary School ('O' Levels)	3 (21.4)
	Finished Secondary School ('A' Levels)	3 (21.4)
	Further Education (attended a Technical College)	3 (21.4)
	Undergraduate/Master's degree	5 (35.8)
AGE AT DIAGNOSIS		
	Mean age in years	55.9 (45-74)
TELEPHONE REVIEW		

	Follow-up time in months	5.6 (3-12)
PLACE OF RESIDENCE		
	Urban	9 (54)
	Rural	5 (36)
OTHER LONG-TERM CONDITIONS		
	Yes	6 (43)
	No	8 (57)

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3 Table 2 Sociodemographic factors of individual patients

Study ID	Sex	Age Range	Education
FG1.1	Male	41-50	Undergraduate/Master's degree
FG1.2	Male	61-70	Further Education
FG1.3	Male	51-60	Further Education
FG1.4	Female	51-60	Undergraduate/Master's degree
FG1.5	Male	41-50	Undergraduate/Master's degree
FG1.6	Female	61-70	'A' Levels
FG2.1	Male	61-70	Undergraduate/Master's degree
FG2.2	Male	51-60	'A' Levels
TI.1	Male	51-60	'A' Levels
TI.2	Female	51-60	'O' Levels
TI.3	Female	61-70	Further Education
TI.4	Male	61-70	Undergraduate/Master's degree
TI.5	Female	71-80	'O' Levels
TI.6	Female	61-70	'O' Levels

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3 Figure 1. Coding tree for themes and subthemes.

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CRediT author statement

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Blain Murphy: Formal analysis, Writing - Original Draft, Writing- Reviewing and Editing
Charlene M. McShane: Conceptualization, Investigation, Writing- Reviewing and Editing, Funding Acquisition
Olinda Santin: Supervision, Investigation, Writing- Reviewing and Editing, Funding
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