Laboratory test ordering and results management systems: a qualitative study of safety risks identified by administrators in general practice

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Laboratory test ordering and results management systems: a qualitative study of safety risks identified by administrators in general practice

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ABSTRACT

Objective

To explore experiences and perceptions of frontline administrators involved in the systems-based management of laboratory test ordering and results handling in general medical practice.

Design

Qualitative using focus group interviews

Setting

West of Scotland general medical practices in three NHS (National Health Service) territorial board areas

Participants

Convenience samples of administrators (receptionists, health care assistants and phlebotomists).

Methods

Transcript data were subjected to content analysis

Results

A total of 40 administrative staff was recruited. Four key themes emerged: 1. System variations and weaknesses (e.g. lack of a tracking process is a known risk that needs to be addressed). 2. Doctor to administrator communication (e.g. unclear information can lead to emotional impacts and additional workload). 3. Informing patients of tests results (e.g. levels of anxiety and uncertainty are experienced by administrators influenced by experience and test result outcome) and 4. Patient follow-up and confidentiality (e.g. maintaining confidentiality in a busy reception area can be challenging. The key findings were explained in terms of sociotechnical systems theory.

Conclusions

The study further confirms the safety-related problems associated with results handling systems and adds to our knowledge of the communication and psychosocial issues that can affect the health and well-being of staff and patients alike. However, opportunities exist for practices to identify barriers to safe care, and plan and implement system improvements to accommodate or mitigate the potential for human error in this complex area.

Keywords: patient safety, risk, test results, human factors, systems thinking, receptionists, primary care

ARTICLE SUMMARY

Article focus

Exploration of general practice administrative staff experiences and perceptions of workplace systems for managing laboratory test results, with a focus on risks and patient safety

Key messages

- Systems for tracking and reconciling laboratory tests ordered with results received are variable, problematic and require improvement
- Communications from doctors to administrators can lack clarity, causing frustration and unnecessary workload
- Maintaining patient confidentiality in busy general practice reception areas can be challenging.
- Dealing with patients' reactions to test results can be emotionally demanding and potentially awkward for administrators.

Strengths and limitations of this study

- The study involved a number of frontline administrators from a large range of general practices in different geographical areas
- Qualitative methods were used with a key workforce group to elicit a more in-depth understanding of this complex area of practice
- The NHS Board areas selected do not reflect the diversity of existing results handling clinical information systems used across Scottish general practice

INTRODUCTION

Workplace systems for managing laboratory test ordering and results handling in primary care are known to be variable, often ineffective and unsafe [1-4]. However, related research to quantify risks and explore patient safety issues appears to be non-existent in the United Kingdom (UK) and wider Europe, although a very limited number of North American and Australasian studies are published [3-4, 5-10]. Arguably this research deficit is a symptom of low levels of interest from policy makers on understanding and resolving patient safety concerns in primary care compared with acute hospitals, although recent UK and European initiatives are encouraging [11-12].

For patients and their relatives, poor test result handling systems may lead to avoidable harm and distress, delayed treatments, unsatisfactory care experiences, and the inconvenience of additional appointments to repeat blood tests or make complaints (1-2). For general practitioners (GPs), missed results and poor test follow-up can lead to delayed clinical judgements on diagnostic and treatment decisions, thereby limiting therapeutic options and potentially impacting on patient safety (3-4). The implications may include formal complaints by patients, loss of trust in the doctor-patient relationship, litigation claims for financial compensation and licensure sanctions by medical regulators (9, 13). At the system level, it is evident that many practices do not have adequate processes for systematically tracking test requests, recording test results (both clinically abnormal and normal), and confirming if follow-up action has taken place before results reports are filed or patients are notified (5-7).

In the UK, and elsewhere, primary care based administrators (most commonly frontline receptionists) work in a demanding and complex role that involves communicating with patients and performing a variety of office duties, many of which have safety importance [14-15]. Tasks undertaken include preparing repeat prescriptions, handling laboratory test results, deciding upon the urgency of home and surgery appointments, controlling patient flow to doctors, making hospital appointments and typing referral letters [14-15]. Often there is a feeling that the duties performed are not appreciated or fully understood by doctors or patients (16)

The involvement of primary care administrators in health services research, particularly with a focus on safety and improvement appears very limited, with a significant proportion of studies undertaken over a decade ago. Examples include capturing perceptions, feelings and experiences related to: work roles and in-service training (14-16); influencing access and continuity of care (17); risks and effects of violence, and impacts on psychological well-being and work performance and satisfaction (18-19); improving communication and providing support to enhance clinical care quality (21); and perceptions of how medication errors can occur (22).

Given the evidence of system failings and patient harm, and the pivotal work role played by this key group, administrators may have important insights into what can go wrong in this area which clearly merits in-depth study. The aim of this study, therefore, was to explore the experiences and perceptions of frontline primary care administrators directly involved in the systems-based management of laboratory test ordering and results handling, with a particular focus on identifying risks that may impact on patient safety and other relevant quality of care issues.

METHODS

This qualitative research was undertaken as part of a wider European study to identify, synthesise and integrate a range of evidence based sources of safety-critical issues affecting laboratory test ordering and systems-based results management in primary care. The overall purpose was to develop ‘good practice’ guidance in this area and build consensus in the UK context and then on a wider European level (23).

Participants and sampling

We contacted via email all general practice managers in three west of Scotland NHS Boards in September 2012 to ask them to invite (on our behalf) representatives from their administrative staff (e.g. receptionists, health care assistants, phlebotomists) to voluntarily attend focus groups on pre-arranged dates. NHS boards were selected on the basis that they had a geographical mix (urban, rural and mixed) of practices and were, therefore, more likely to have different systems for managing results (e.g. mostly computer based, paper-based or mixed computerised and paper systems), which we judged important in reflecting and influencing the types of patient safety risks faced by diverse practices. A convenience sampling strategy was decided upon because of the limitations of purposively selecting participants caused by the time-limited nature of the study and the pre-arranged interview dates.

Focus group interviews

Five group interviews were held in west of Scotland health care settings in Glasgow (n=3), Motherwell (n=1) and Kilmarnock (n=1). LH moderated each session and assisted the discussion with the aid of a brief topic guide (Box 1), informed by issues previously raised in the literature. Participants were asked to view 'patient safety' pragmatically in terms of results handling incidents, or potential incidents, which they would not like to happen to themselves or relatives. They were encouraged to speak freely about their experiences and perceptions of all aspects of the results management systems in their practices. Assurances were given that their views would be treated in the strictest confidence and that they would remain anonymous on transcripts. Sessions lasted between 45 and 70 minutes and were digitally recorded and transcribed with permission. Contemporaneous field notes were also taken.

Data analysis

The transcripts were subjected to conventional qualitative content analysis [24] - to provide knowledge and understanding of the phenomenon under study [25] - on an iterative basis as data collection progressed. Data were systematically coded, categorised and initial themes identified by LH. Cross-checking of data categories and themes with the transcripts was undertaken by PB to enhance validity. Categories and themes were modified and reduced by merging and linking them after joint discussion between both researchers, with disagreements resolved by consensus. To validate further, we emailed a summary of the draft findings to study participants for critical comment and input, but none provided feedback.

RESULTS

All 40 staff who agreed to participate from the three discrete Health Board regions approached, attended the five focus group interviews (Table 1). We achieved data saturation by the fourth focus group, with the final group interview affirming this. Almost all participants were female (n=39, 97.5%), with 25 based in urban practices, nine from semi-rural practices and six from rural practices.

Four principal themes were identified:

1. System variations and weaknesses
2. Doctor to administrator communication
3. Informing patients of test results
4. Patient follow-up and confidentiality

System variation and weaknesses

A ‘grey area’ of mixed computerised and manual processes that underpinned results handling systems was described. For some, particular importance was placed on manually recording all blood tests ordered and reconciling the results when received from the laboratory. For others, the high volume of tests ordered made the workload involved in reconciling tests ordered with results received ‘impossible’ and this impacted on what was communicated to patients, while there was also a reliance on patients to contact the practice for test results .

Many participants reported using both electronic and paper copy results systems for the same patients to act as a safeguard because of a range of perceived technical and user problems receiving and managing results electronically. The paper copies were also reviewed and then scanned into patients' records and archived. This was viewed as task duplication and a source of frustration because of the reconciliation workload involved. There was consensus that the lack of a tracking system for results handling is a known risk and ongoing concern and needs to be addressed and improved within many GP practices. It was the experience of some participants, that if a patient fails to contact the practice, even if the result is abnormal, they might never receive this information or it will only come to light if they attend in future with a related or different problem.

> *"…there could be maybe three or four bloods done and you get two results and you will be relaying the information* [that] *your results were normal and one or two have still to follow…"* (Focus Group 2)
>
> *"…it is coded when they have had a sample taken and every day we run a search five days before to see what bloods were taken and make sure they have all come back."* (Focus Group 3)
>
> *"…we check that every day we have a blood book… they go through the whole lot and check when it [the result] comes back in".* (Focus Group 1)
>
> *"…putting the EMISS* [information system] *results into the patient's notes and then the Docman results is going into the patient's notes…defeating the purpose".* (Focus Group 1)
>
> *"…the onus [is] always on the patient because they are asked to phone back in to get their results…"* (Focus Group 3)
>
> *"…someone is phoning and we are telling them (the result) is normal and the next day two more come in and there is something wrong with them or one went missing, if that patient didn't phone in for the result and that result has gone missing, if the blood has gone missing before it has even got to the lab, or there has been some sort of lack of communication with the bloods they wouldn't know if it is back or not if the patient phones up and asks for the result and then we would chase the lab and unfortunately the patient doesn't know what bloods are being taken".* (Focus Group 4)

Communication between doctor and administrator

Mixed feelings of anxiety, frustration, pressure or awkwardness emerged often caused by limited, unclear and ambiguous test result communications by doctors which would then require further clarification. For many, comments written by doctors on results reports for staff to relay to patients sometimes "*don't make any sense*". Some participants also felt inhibited in what they can say to patients, particularly when advised by doctors never to communicate anything other than what is in their messages. Contacting doctors to clarify the meaning of the message and also ask the patient to telephone back added to workload and inefficiency. Approaching some doctors for clarity could be daunting for some participants in these situations because they may exhibit discourteous behaviours.

A whole series of common terms and words routinely used by doctors in communicating results were described and debated – *'satisfactory', 'acceptable', 'normal', 'slightly abnormal', 'no action required'* – which both staff and patients struggled to make sense of depending on the clinical context, and particularly where the patient queries the result or reacts negatively. For some, this was compounded by a sense of uncertainty in their practices that they are not always doing the same action when communicating results. This limited understanding combined with incomplete information made available to staff impacts on communication difficulties with patients.

> *"…he might bite my head off…it depends which GP it is as well…some are more approachable".* (Focus Group 5)
>
> *"…a result will say abnormal but it might not necessarily be abnormal to the doctor or where it's maybe satisfactory compared to last month's bloods but it doesn't mean they are normal…".* (Focus Group 2)
>
> *"I feel as if they don't really give us enough information to pass it onto the patient…sometimes the doctors are not very detailed"* (Focus Group 1)

Informing patients of test results

Differences were apparent in how participants were instructed to inform patients of blood test results and who undertook this task. Some were only 'permitted' to communicate to patients exactly what the doctor had written in the results report, while others were given less guidance on this issue. This was exemplified in one group discussion around Cholesterol results which highlighted how some were permitted to pass on actual Cholesterol levels while others were instructed never to do this.

Participants had mixed feelings about notifying patients of blood test results. Many described some level of anxiety and uncertainty when communicating test results, with a few describing the process as 'scary' or 'intimidating'. This was especially so when they were new in post, as they were nervous and unsure if they were relaying the correct information, with some suggesting they tried to avoid this task. Some anxiety related to using unfamiliar medical terminology that has no meaning for them. For some the process is straight-forward and unchallenging most of the time, while it was stressful for others but this lessens to some extent as confidence grows with experience. However, this depended on the actual result and what they were instructed to tell the patient, with most agreeing the process was difficult when communicating 'bad news'.

Dealing with a patient's expectations and reactions when informed of a test result was also a challenge, with many participants' feeling pressurised into engaging in further discussions. When informed their results are normal, patients can sometimes appear to be “unhappy”, “disappointed”, or even “astonished” that this is the case given their perceived clinical condition, leading them to seek clarification, double-checking and re-testing. Some patients also assumed that administrative staff are able to interpret the result and provide further clarity. When informed a letter is to be sent to them, or if asked to return for a repeat blood test, patients may also become visibly anxious or agitated inducing stress and discomfort in staff who felt very limited and inadequate in terms of providing reassurance.

There was consensus that a clinician would ideally be the most appropriate person to communicate test results to reassure patients, provide further explanation and enhance safety. However, it was acknowledged by most that they have a job responsibility to perform this task and that in most cases test results are normal, while many of the complicated abnormal results and associated emotional impacts are usually, but not always, handled by practice clinicians.

Many often felt pressured to communicate to patients more than they are comfortable with, with some suggesting that giving results should not be part of their role because they are not clinically trained. For some, they feel at times *"pushed"* by the patient to give them more information, however most recognise this as potentially *"dangerous"* in terms of giving out inappropriate information and perhaps incurring the wrath of the doctors.

> *"I don't even know what I am talking about and I am trying to explain* [test results] *to somebody".* (Focus Group 2)
>
> *"…when I started giving out the results I was terrified I didn't relish the prospect"* (Focus Group 2)
>
> *"I always feel a wee bit anxious when I am giving out these kind of results because for one you are not sure if what you are telling them is the right thing and you don't know how they are going to react"* (Focus Group 3)

"…we give out, for example, urine results although the GP's not seen them because it is absolutely spot on clear, we always say doctor hasn't seen this result yet it is a provisional result, should there be anything that the Doctor needs to talk to you about then we will get back to you, I put on that result 'patient informed negative for infection trust this was ok' that is my comment it goes back to the GP, it is always seen". (Focus Group 3)

"I think a nurse or someone with some clinical background should be dealing with it". (Focus Group 2)

"I find it hard when they are ringing for results and you need to make them an appointment and they go into panic at the end of the phone and you can't give them any more information, I am not medically trained I can't tell you then you have got nobody to ring them back". (Focus Group 1)

"…[communicating]*a bad result…just as a human being there is something you are seeing* [the result] *before that patient knows*." (Focus Group 5)

"You don't want to get involved in conversations like that [going into detail about results], *they just go wrong"* (Focus Group 5)

Follow-up and confidentiality

Failure to contact patients despite making numerous telephone calls and sending letters was a continual source of frustration, while patients failing to make contact for test results despite being instructed to at previous appointments emerged as key follow-up issues. Protecting patient confidentiality was a problematic area of practice, particularly in face-to-situations in busy reception areas which lacked private spaces. Some participants would refuse to give results over the telephone if they were unable to verify the caller's identity, while others admitted to deviating from protocols by communicating results if they personally knew the patient or a relative, particularly where the patient was ill or had a disability. Caller identification systems also caused problems for staff and patients in circumstances where the practice number shows up on the patient's home telephone system and they subsequently telephoned back, but practice staff are not immediately aware who made contact with the patient and why, which causes additional delays and workload to resolve the issue.

The use of signed authorisation forms by the patient and automatic systems alerts to authorise permission to another person (e.g. partner) to receive a result were also in common usage. However some practice policies insisted on seeing and receiving patients' authorisation in person, particularly where the patient did not speak English.

The practices of many participants had an age-cut off for parents who may telephone to receive their child's results on their behalf, which can cause upset and anger when administrative staff refuse to comply with parents' requests. When unable to contact patients by telephone leaving the practice contact number and not explaining who is telephoning and why, was a common policy for some. Others would not leave any message unless the patient had explicitly agreed to this. Some participants described potential breach of confidentiality incidents where colleagues had telephoned patients and left voicemail messages on home telephones explaining who was calling and to return the call to receive their blood test results.

Mixed work practices emerged over where and how to communicate test results with many participants favouring face-face contact rather performing this task over the telephone, although some reported that patients can dislike telephone contact. Maintaining confidentiality at the reception desk was a major concern, with some practices preferring not to give out results here because it was difficult to maintain privacy, particularly when very busy. Some participants agreed the onus was on the patient in this situation and that if they choose to ask for test results in an area where they could potentially be over-heard then they were happy to communicate them, although in most cases patients are being informed that the result is normal or to telephone back.

> *"…a lot of them just don't phone back, you're maybe getting them three months down the line saying, I had bloods done".* (Focus Group 2)

> *"…there are lots of issues at the front desk that can be an absolute nightmare for us…it is difficult you have got a crowd at the door and someone is wanting to get their [test] results".* (Focus Group 4)

DISCUSSION

The main safety risks experienced and perceived by GP administrators in this study covered a wide range of system level weaknesses, doctor-administrator-patient communication issues, maintaining patient confidentiality, following-up patients and coping with their reactions to, and expectations of, blood test results. Participants' accounts of systems, communication and psychosocial problems expose the potential for error, inefficiencies and frustrations associated with handling test results.

Strengths and limitations

The use of focus groups enabled us to explore this under-studied issue in greater depth with an important part of the relevant workforce than we would have done, for example, using a questionnaire survey. All participants who volunteered a willingness to participate actually attended the group interviews which may be an acknowledgement that this is an issue of high interest. The discussions were lively and we were satisfied that every participant was able to make an adequate contribution. Limitations include the fact that study participants may not reflect the profile and experiences of the administrative workforce, which is a difficult issue to resolve for all qualitative studies. We were also unable to link participants' views and experiences with the demographics of the practices in which they were based and the systems used. Other limitations are that some practices use only nurses to communicate test results to patients while practices in geographical areas not covered use full electronic tracking systems for results handling. Addressing these issues would have enhanced the robustness of the study and the strength of our findings, which should be viewed with some caution given this context.

The reported weaknesses of practice systems is comparable with previous research which found that participants experienced multiple problems in the different process steps involved in results handling, with inadequate systems and lack of standardisation being identified as contributory factors [5, 26]. Additionally, difficulties arising in the clarity of verbal and written communication between doctors and others, including the potential for perceived disrespect or rudeness [27], are a recognised hierarchal problem which may also impact on safety in the workplace (3, 28). In this regard, there are recommendations for doctors to develop a greater understanding of the administrator's work role (16, 20). Although administrator-patient communication has been the subject of limited research previously – mainly focused on the administrator as a barrier to accessing care – our findings suggest that some administrators struggle with the inter-personal and emotional demands of informing patients of test results and handling follow-up queries. Dealing with patients' sometimes difficult expectations and reactions, and feeling caught between the demands of doctors and patients are previously reported as workplace stressors for administrators in primary care (16). Finally, the issue of patient confidentially being breached in the reception waiting area is a known significant event [1], but can sometimes be difficult to mitigate given the lack of private space availability afforded in the design of healthcare facilities and the attitudes of staff and patients towards confidentiality (29-30)

One way to interpret and explain the findings and consider the wider issue of test result handling at the practice level is to understand the workplace in terms of sociotechnical systems theory, which is highly influential in human factors science and application (30-32). In essence this suggests that the success of any workplace system or technology is strongly interdependent on the social relational contexts of work organisation, rather than just on the systems or technology itself. There is a growing interest in the need for healthcare professionals to be trained to understand and implement human factors and ergonomic principles in the workplace [23, 33]. Taking a systems approach to designing job tasks and work processes to accommodate human capabilities and limitations, and therefore minimise the risk of errors, is an important element of this discipline [33-35]. There appears to be a clear alignment between many of the social and technical interactions and interdependencies of test results handling systems uncovered in this study (and the wider literature) that would benefit from a human factors approach.

Patient safety research is still in its infancy, particularly in primary care [11-12, 36]. Although we know from limited taxonomy studies undertaken that test results handling is a major issue [1-2, 37-42], we need a more in-depth understanding of the related human-task-system interactions and socio-technical risks inherent in the practice systems we design if potential solutions to problems are to be realised [43]. Involving key staff groups such as administrators and using qualitative research methods to explore these issues is, therefore, paramount to advancing knowledge about practice culture (e.g. leadership behaviours and commitment to improving safety), psychosocial issues (e.g. staff motivation and input to relevant decision-making) and technical difficulties (e.g. reliability of test result handling processes and information technology). Arguably all will have to be addressed before we can begin to make progress in re-designing and evaluating improved test result handling systems to minimise errors and patient harm.

CONCLUSION

The study further confirms the safety-related problems associated with results handling systems in primary care and add to our knowledge of the communication and psychosocial issues that can surface at the doctor-administrator and administrator-patient levels, potentially affecting the health and well-being of staff and patients alike. However, they provide an opportunity for practices to identify barriers to safe care, and plan and implement system improvements to accommodate or mitigate the potential for human error in this complex area. A potential learning need to develop educational solutions for the primary care workforce to strengthen human error knowledge, whole system awareness, team working and internal communications is also apparent.

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Contributors

PB conceived the study idea, acquired funding, assisted with the study design, data analysis and interpretation, and the drafting and critical revision of the manuscript. LH assisted with the study design, led the data collection, analysis and interpretation and helped draft the manuscript. JM contributed to the drafting and critical revision of the manuscript. All the authors have approved the manuscript.

Competing interests

None.

Ethical approval

This study was pre-screened by the west of Scotland research ethics committee but was judged to be service evaluation.

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Box 1: Focus Group Topic Guide

Study Aim:

To explore experiences and perceptions of frontline administrative staff directly involved in the systems-based management of laboratory test ordering and results handling in general medical practice.

Topic Guide Questions

Focus group participants were asked:

- about the main problems and frustrations with their practice systems
- how these might impact on patient care and safety
- how they feel about their job role and their interactions with other staff groups
- how they feel about their job role and their interactions with patients

Table 1: Focus Group details

Focus Group	Location & NHS Board area	Participants (n)
Focus group 1	Glasgow, NHS Greater Glasgow & Clyde	6
Focus group 2	Glasgow, NHS Greater Glasgow & Clyde	10
Focus group 3	Glasgow, NHS Greater Glasgow & Clyde	9
Focus group 4	Motherwell, NHS Lanarkshire	6
Focus group 5	Kilmarnock, NHS Ayrshire	9

Recommendations for Change

Practices should consider implementing:

Training and support for administrative staff on the safe communication of test results to patients and in dealing with reactions and expectations.

Training and support for all staff groups on the basic principles of whole systems thinking and human factors practices

A standardised process for tracking and reconciling tests ordered with results received that is co-designed, fully understood and used by all relevant staff.

A standardised process for following-up patients with clinically significant abnormal results in order to prevent a reliance on the patient to make contact with the practice.

A standardised set of words, terms and phrases - agreed between clinicians and administrators - to enable administrators to communicate and explain common test results to patients using language that is clear, unambiguous and promotes patient safety.

A standardised process that guides how and how often practices attempt to contact patients who require follow-up that is fair and reasonable from a medico-legal perspective.

A standardised process that feasibly minimises the risk of breaching confidentiality by staff when communicating tests results to patients face-to-face or over the telephone (including potential redesign of working areas to enhance privacy).

A commitment by doctors and nurses to 'shadow' administrative staff for a short period of time to acquire a better understanding of their job roles and tasks undertaken, and related difficulties and anxieties.

Laboratory test ordering and results management systems: a qualitative study of safety risks identified by administrators in general practice

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Social support for South Asian Muslim parents with life-limiting illness living in Scotland: a multi-perspective qualitative study.

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ABSTRACT

Objective: To explore experiences of social support needs among South Asian Muslim patients with life-limiting illness, living in Scotland, who are parents of young children.

Design: Secondary analysis of data from a multi-perspective, longitudinal, Scottish study involving in-depth semi-structured interviews with patients, their nominated carers and healthcare professionals. Data were analysed using Interpretive Phenomenological Analysis.

Setting: Edinburgh, Scotland

Participants: Eight first generation South-Asian Muslim palliative-care patients with children under the age of 18 (n=8), their carer (n=6) and their healthcare professional (n=9).

Main outcome measures: Access and provision of social support in palliative care

Results: Open-ended qualitative interviews identified four main themes: (1) parental sadness over being unable to provide tangible support; (2) parental desire to continue to provide emotional support; (3) limited availability of informal social support networks; and (4) differing perspectives between health care professionals and patients on patient access to social support sources, with a subtheme being the capacity of male carers to provide social support.

The South-Asian parents at the end of life had limited access to extended-network support. Gender roles appeared as challenging for healthcare providers who at times overestimated the amount of support a female carer could provide and underestimated the amount of support male carers provided. Implications for practice include the need for greater awareness by healthcare providers of the social support needs of ethnic minority and migrant parents with life-limiting illnesses and especially awareness of the importance of the role of both male and female carers. Further research is needed to explore how the timing of migration impacts the need for and availability of tangible and emotional informal social support among ethnic minority parents with life-limiting illness.

Word Count: 275 words

ARTICLE SUMMARY

Article Focus

- To explore experiences of social support needs among South Asian Muslim patients with life-limiting illness, living in Scotland, who are also parents of young children.

Key Messages

- South Asian Muslim parents with a life-limiting illness desired to maintain their emotional support roles as parents and needed assistance from formal social support services.
- Increased awareness is needed among healthcare providers both regarding the existence of inconsistent and fragile social support networks in ethnic minority families and about gender roles of carers.
- Future research is needed on: the perspectives of children with parents with life-limiting illness, insight into the influence of timing of migration and acculturation on social support needs and access to services the perspectives of male carers with South Asian background and the relationship between gender, migration and access healthcare services.

Strengths and limitations of the study

- The major strengths of the study include: Results were frequently discussed with members of a multi-disciplinary team; a large response rate (96%); diverse and broad range of participants highlighted that further research is needed on the relationship between timing of migration and access to palliative care services; and, the use of multiple perspectives (patients, health-care providers, carers).
- The major limitations of the study were that diverse and broad range of residency status and acculturation related factors led to inconsistencies in themes, missing interviews with three out of the five male spouses of patients. The lead researcher did not collect data and therefore there was considerable distance from the data. However, in the scope of a the secondary analysis method allowed the data to be viewed from a different perspective soliciting new themes.

INTRODUCTION

Social support has been found to be associated with an increase in quality of life for patients with life-limiting illness and also for their partners, children and other family members [1 2 3 4 5 6 7]. Social support consists of addressing tangible needs such as assistance with transportation, home and personal care, as well as emotional support such as being listened to, understood and comforted [5]. Both tangible and emotional support may be provided through informal and formal social networks. Informal social support is obtained through available family, friends and communities, which may include both community and religious networks. Formal social support is obtained through professional service providers such as doctors, nurses and social workers [Figure 1] [1 2 3 4 6 7].

Having a parent with life-limiting illness, or who has died, has been linked to stress, anxiety and poor psychological health in children and adolescents [3 4 8 9 10]. Disability, pain, emotional distress and the need to attend for long-term treatment and/or palliative care makes it hard for parents to provide the same level of support as before they became ill. Moreover, parents with life-limiting illnesses struggle to maintain normality for their children in helping them with their daily activities such as going to school or for outings [11 12 13 14 15 16 17 18]. Social support allows children to engage in important coping processes such as discussing their feelings, developing enjoyable memories with their parents and being able to temporarily take a break from stresses in the home [3]. In order to maintain this role, parents often desire the help of formal social support services in order for their children to be able to live as normal daily lives as possible in the context of life-limiting illness [11 12 13 14 15 16 17 18].

Concerns have been expressed that ethnic minorities in the United Kingdom (UK) are less likely to use formal supportive care services than the ethnic majority population [19 20 21 22 23]. There has been a debate whether this is due to less need of services, partially due to the healthy migrant effect whereby economic migrants move for work and tend to be healthier and/or younger compared to the ethnic majority population, or due to inequalities in access and acceptability of healthcare [20 21 22 23].

Factors found to be associated with the lack of uptake of palliative care services among ethnic minorities include socio-economic status, attitudes towards palliative care, lack of knowledge of available services, mistrust of healthcare providers, lack of referrals and dissatisfaction with healthcare providers [7 22]. Referrals or lack thereof may be associated with healthcare providers' perceptions that ethnic minority patients have large networks of extended family members to rely on for support, a stereotype that has now been largely refuted in the literature [24 25 26 27].

Public health policies in the UK during the 1990s, particularly those directed at South Asian communities focused on the development of social support services stemming from the community. Many of these policies failed to reflect shifting patterns and laws regarding migration, changing household structures towards a nuclear family structure and women's changing role in the workplace . More recent research has shown that ethnic minorities and migrants in particular have a more fragile social support system than previously thought and that, even for those with large extended social networks, these networks may not provide adequate social support [5 25 26 27 28 29].

The majority of existing studies on South Asian experiences of palliative care in the UK focus on the experience of care for elderly patients or care of ill children[30]. There is however little previous work investigating the social support needs of South Asian parents living in the UK who are both severely ill and have young children who may face complex challenges in coping with both the physical, mental and social consequences of life-limiting illness and at the same time prove care to their young children. More insight into the experience of reconciling parenthood with life-limiting illness is needed since this will enable the identification of ways of providing support to families in difficult circumstances. Specifically, it is to meet parents' desire for social support services which allow them to maintain their roles as parents. Moreover, children who have a parent with life-limiting illness require social support in order to engage in important coping processes, such as going on outings, and maintaining normalcy in their lives. We sought therefore to explore the experiences of social support among South Asian Muslim patients with life-limiting illness in Scotland who are parents to young children.

METHODOLOGY

This study is a secondary analysis of a qualitative data constructed as part of a large multi-perspective, longitudinal study aimed at understanding experiences of Sikh and Muslim South Asian patients at the end of life (entitled; 'Developing services to meet the end-of-life care needs of South Asian Sikh and Muslim patients and their families in Scotland'). A secondary analysis was conducted in order to explore in-depth the social support needs of a subset of Muslim patients who were parents with young children. We present here a brief summary of the methodology since a more detailed description of the recruitment process, data generation and ethical considerations have been presented elsewhere [31].

In the original study purposive sampling was used and patients were approached through healthcare and social care professionals, religious leaders, community leaders and personal contacts. Patients were selected on the basis they were given a diagnosis of cancer or another life-limiting illness and that they had a prognosis of living less than one year. Once patients were contacted and expressed interest to take part in the study, they were asked to nominate and give consent to contact their primary carer and healthcare provider. Maximum variation sampling was used to recruit a diverse range of informants with varying socio-economic status, gender, age, malignant and non-malignant life-limiting illnesses, educational background and country of birth [31].

In-depth semi-structured interviews were conducted with a total of 25 patients and their nominated carers and nominated healthcare professionals, yielding a total of 92 interviews [31]. Interviews with patients and carers were conducted by a trilingual researcher and were conducted in Punjabi, English and/or Urdu. The interviews were then transcribed and translated by both the trilingual researcher and a trilingual secretary. Healthcare professional interviews were performed by either the tri-lingual researcher or another member of the research team. Up to three interviews were conducted with patients and when necessary, bereavement interviews with carer's were conducted at 8-12 weeks after the patient's death. Interviews were done in stages, stage 1 was the initial interview, stage 2 took place approximately 8 weeks after the initial interview and stage 3 took place 18 weeks after the initial interview. Data was collected in 2004. Interviews were undertaken until saturation was reached

Secondary Data Analysis

In this secondary analysis, only interviews of Muslim patients with children under the age of 18 (n=8) were analysed. A total of 36 interviews were analysed i.e. from eight patients, their carers (n=6) and healthcare professionals (n=9) [Table 1]. For one patient, two healthcare providers were included in the study. Only interviews of patients with children under the age of 18 were analysed. We decided to only include Muslim patients in this secondary analysis because there was only one Sikh participant with a child under the age of 18 and this child was not residing in the United Kingdom.

The topics discussed in the interviews relating to being a parent at the end of life varied between patients, carer's and healthcare providers. Specifically, discussions with patients included their perceived needs for palliative care services, their experiences of formal care services, impact of the illness, their relationship with healthcare providers and decision making within in the family. Relevant topics discussed with primary carer's included the impact of the patient's illness on the family, the carer's needs, the history of the illness from the carer's perspective and the patient's preferences for social support from the carer's perspective. Topics discussed with the nominated healthcare provider included their perspective on the social support needs of the patients and their family and what the healthcare provider provided themselves in contrast to others [31].

Data were analysed using Interpretative Phenomenological Analysis (IPA) as described by Griffen and May [32] as well as an analysis of multi-perspective interviews as described by Kendall [33]. According to Griffen and May [32], IPA draws upon the philosophy that experience is formed based on the perceptions of the participants of the world around them through daily tasks, their perceived geographical or societal location and their interaction with those around them. Additionally, in order to operationalize the meaning of social support, this analysis draws upon the surrounding the meaning of care and the perception of who is available to care as a defining element of understanding experience. Multiple-perspective interviews were conducted across time to contextualize the social support experiences of patients, and to contrast varying perceptions of the patient, carer and healthcare provider. According to Kendall [33], in the presentation of results citations can be both integrated and/or compared in order explore the aim. In this secondary analysis, multiple perspectives were integrated to explore commonly expressed needs of social support and compared to explore different perspectives of need between patients, carers and healthcare providers.

IPA is a method that lends itself well to analysing the lived experience of social support. This is because with IPA the researcher takes what an informant sees as a daily experience, such as homecare or driving children to school and places them into a larger theoretical framework [32]. IPA allows the researcher to explore the different perceptions of how the participants relate to their life-world and how they experience social support. This method is important since much of the current literature on palliative care experiences of ethnic minorities refers to the lack of referral by healthcare professionals and the prevailing assumption that ethnic minorities have available large social support networks.

As described by Griffen and May [32], the analysis was conducted in four steps. First, a close reading of the selected interviews was performed and initial thoughts were recorded. For this stage Open Code software [34] was utilized in order to record initial codes and select meaning units. In identifying meaning units, the definition of social support was divided into emotional and tangible support as well as awareness of the source of the support, formal or informal [see Figure 1]. The next step was the interpretative phase where more abstract ideas are generated about the lived experiences of social support. Finally, themes were identified and grouped into clusters under super-ordinate themes. Negative data or disconfirming cases were continuously sought.

Ethical Approval

This study received Ethical Approval from the Lothian Research Ethics Committee (Scotland). Care was taken in order to ensure that participants understood the study and could give informed consent. Special consideration was taken in gaining consent from participants who were illiterate in any language. In reporting the data, participant's identities were disguised in order to maintain confidentiality. Researchers were sensitive in their discussions of death and dying, this especially if the participants were unaware of their prognosis or diagnosis.

RESULTS

Four themes were developed in relation to experiences of social support needs among South Asian Muslim parents with a life-limiting illness. These are described below together with supporting illustrative data.

Sadness over being unable to provide tangible support: I cannot do anything for my children

In general, patients expressed sadness over no longer being able to provide tangible support and perceived this as a loss of an important part of their parenting role. As one patient described when asked about the overall experience of having a life-limiting illness,

> R: What is the most difficult thing for you?
>
> P: I cannot do anything for my children…[crying].
>
> (Patient 1, Male, Stage 1 interview)

Often the experience of multiple losses caused by life-limiting illness was expressed in the context of family life which for these South Asian patients was important to maintain actively. Patients struggled to uphold their responsibilities within both immediate and extended family. They particularly grieved being unable to provide social support for their children.

The most important expressed need for tangible support was transportation. Patients and their carers frequently discussed the importance of availability of transportation, particularly in relation to picking up and dropping off children from school, taking outings and attending doctor's appointments,

> Sometimes [I] had to make [my] son take a day off school when I needed to go and see him [patient] in the hospital. Even now, when I take him [patient] to see the doctor, my son will need a half day off school.
>
> (Carer, Patient 2, Female, Stage 1 interview)

Patients described children's desire to go on outings with their parents. However, ill parents and some carers, particularly female carers, were often unable to drive. Patients reported a longing to be able to take outings with their children which they perceived to be important elements of a happy, care-free childhood,

> My eldest son did say to me once those other children's mums take them out and I would like to do that [crying]. Hence I started to drive to the shopping centre and sit in the car. I couldn't go in because I was feeling so tired…

(Patient 25, Female, Stage 1 interview)

The need for transportation was most acute when participants had recently arrived in Scotland and did not have resources such as cars, driving licenses or a support network to help picking up and dropping off children from school or engaging in enjoyable activities.

Desire to provide emotional support: By God's grace I still have that power

Patients desired to provide emotional support for their children, very often because they could only provide limited tangible support. In one parent's words,

> See if I had, I don't know how to put it so it sounds politically right, if I had suffered any mental problems, then it would be different. Because I would not be able to keep my family together, whereas, through God's grace, I have still got the power. I have still got that ability to step in and help my children when they have a problem. Or if we have a problem, to sit and talk like an ordinary family. Only thing is that I can't do anything for them.
>
> (Patient 4, Female, Stage 3 interview)

The same patient added that at one point in time her daughter was offered to join a support group for young persons with parents who suffered from life-limiting illness. The daughter refused this offer. The patient explained she respected her daughter's decisions, stating she wanted her daughter to experience as much normalcy as possible,

> Yes, at one point, they did offer support for my children, joining a group or something like that. And my daughter said "no, I don't want it". And I said, well, I don't want them to feel any different, I just want them to grow up. Have, as much as possible, a normal up-bringing. The choice was given to her and she refused, so that's fine.
>
> (Patient 4, Female, Stage 1 interview)

Some parents were happy to receive both tangible and emotional support services, though there were cultural differences which sometimes prevented full access to these services. For example, in regards to emotional support services for Patient 5, the healthcare provider reported that children, despite parents' interest, had never attended the offered group therapy session due to a scheduling conflict. This conflict was due to the children needing to attend mosque at the same time as the group therapy session. Their children participating in religious activities was by many patients perceived as important both for their children's upbringing and for their present and future emotional wellbeing. Culture – and more specifically religious – aspects shaped experiences and priorities among patients as exemplified by the emphasis bestowed upon religious learning for their children. However, both the patient and carer were happy to receive materials such as a children's book to discuss with their children,

> I first met them and told them a bit about the leaflets and the resources that are around for children to help adults talk to children about cancer […] they were quite happy with it in English… em there's a book I did give to them which was one was called Mummy's ill…and kind of explains about cancer and what that is and what chemotherapy is and what is radiotherapy, all that sort of things.
>
> (Healthcare Provider, Patient 5, Stage 1 interview)

Another form of emotional support parents wanted to provide was through teaching their children religious practice since this was considered an important part of parenting. One patient hoped that teaching her daughter religious practice would give her daughter emotional support both now and in the future,

> The other thing that worries me is that she is 13, she does not know namaz [daily prayer] yet, she is still reading the Qur'an. I was saying to her we really need to get on top of that because that is a big obligation as a parent… I say to her that that is really important because I feel that, you know, sometimes you will get comfort from that as well.
>
> (Patient 3, Female, Stage 3 interview)

Parents referred to religion in terms of their own emotional coping, performing an important duty as a parent and also providing emotional support for their children. However, they did not describe themselves as relying on or gaining tangible social support from religious networks.

Patchy informal social support networks: We tried to get my sister over…

The responsibility for tangible support fell largely onto the primary carer, most often the spouse of the patient. One of the carers described taking on the majority of her husband's care which was even more strenuous because she had a young child,

> I did it myself, I still do now….Enough, what else can I do, he needs care. I used to go out to work and I had to leave that about 6 months ago. It was difficult having a young child too.
>
> (Carer, Patient 2, Female, Stage 1 interview)

Extended family, when available, frequently provided support by taking children for overnight visits or watched children while parents were attending doctor's visits or were admitted to hospital. One patient, in the only family where both the husband and wife were born in Scotland, described the role extended family played,

> Sometimes we would need to stay in overnight, and my mum would come up with my brother and take the two of them away. Sometimes her mum and dad would come and take them. So the least you have to worry about…
>
> (Patient 13, Male, Stage 3 interview)

However, the availability of extended family members varied and participants cited that family members had their own families to care for.

In some families, extended family members lived in other cities or countries and grandparents often had their own life-limiting illnesses. Some families applied for visas for their family members to come from abroad and help with daily life, as one carer explained,

> We tried to get my sister over from (country) for about six months. She could come and help with the child by picking him up from school.
>
> (Carer, Patient 2, Female, Stage 1 interview)

Visas for healthy family members to come and help with social support needs of those who were ill were sometimes denied, even though healthcare professionals wrote visa support letters.

Insecurity and differing perspectives on social support sources: I've got to leave on healthy parent behind

Patients who received formal support services were quite pleased with the services they received. However, some healthcare providers mentioned that they were sometimes unable to gauge the amount of informal social support patients were receiving from family and community networks which would inform the amount of formal social support services needed. As one healthcare provider mentioned,

> R: Is there anything else that you want to say that I haven't asked you about?

> P: Em, how much support do people get from Mosque, I mean is it like here? They have to belong to a Church and then the Church rallies round or is it different with the Mosque?
>
> (Healthcare Provider, Patient 1, Stage 1 interview)

The same healthcare provider in response to a question regarding how to increase social support services for South Asians in Scotland, referred to a breakdown in communication,

> I was in Glasgow on Friday and was told there's a man, Muslim man whose looking after his mum single-handedly and washing her, bathing her and you know it's really not the kind of thing you'd expect from a man to do for a female, either he's not getting the support or what he's getting not just good enough for his mother, you know there are issues there, there's a breakdown somewhere.
>
> (Healthcare Provider, Patient 1, Stage 1 interview)

Other patients referred to on-going discussions with their healthcare provider regarding family availability to provide care when requesting access as to services. One patient described an on-going conflict between herself, the carer and healthcare providers regarding who in her family was available to provide support,

> But they [formal social support provider] keep telling me "you have family." And I say, "yes, what do you want me to do? Kill them before their time?" I'm on my way out; I've got to leave one healthy parent behind.
>
> (Patient 4, Female, Stage 1 interview)

The nominated healthcare provider explained how resource constraints influenced the agency's policy towards provision of support, making it more likely they would ask family members to provide care,

> … our department, Community Care, has changed from the early days – "we treat this person as an individual, we don't rely on the family" and all the rest of it – to the complete opposite. If there's family there, they are expected to help because resources are so tight. So initially it was "couldn't the children be involved."
>
> (Healthcare Provider, Patient 4, Stage 1 interview)

In contrast to the above statement made by a healthcare provider, parents felt very strongly against their children being relied upon to provide care.

It is important to note that several healthcare providers mentioned resource constraints in regards to providing culturally sensitive services including translated leaflets and providing a choice of homecare attendants. For example, the carer of patient 5 states, while he was open to services such as homecare and a social worker to take the children for outings, cultural differences, such as the homecare worker refusing to take off her shoes inside the home, made care unacceptable,

> A worker comes in she hoovers the place washes the dishes irons things like this, I asked her to take her shoes off and put some slippers on that we had, she didn't say a word, had some tea and went off after doing her work…she went back and complained they told me to take the shoes off this that and the other. I got rude phone call from her boss. "Excuse me, did you tell her to take her shoes off"?
>
> (Carer, Male, Patient 5, Stage 1 interview)

When the carer requested another homecare attendant, he was told there were a limited number of attendants available. Hence, this interview suggests that at times it was difficult for patients to receive culturally sensitive formal social support services.

In summary, , patients were open to receiving formalfrom social support services, however, cultural differences and constrained resources prevented patients and their family members from fully accessing social support services.

Differing perceptions of social support and the role of gender

In discussing the amount of available informal social support, healthcare providers often referred to the gender of the carer which by some were perceived to be shaped largely by cultural factors. Specifically, some healthcare providers assumed female family members were more involved in providing social support for the patient and the children in the family compared to male family members. Healthcare providers at times referred to their previous experience with South Asian Muslim patients in palliative care settings in the UK, and a few described also that their perspectives stemmed from experiences working in Muslim countries,

> It has been my experience with the few other Muslim women I have dealt with as well – they have come on their own without their husbands or their partners have seemed to be very much in the background. Muslim women seem to have a more distant relationship with their husbands….White

> couples do seem to come as equals – may well be that they are estranged equals – but they are there as equals, it seems that South Asian women are much more submissive They are more clearly different. Husbands often seem so much more traditional.
>
> (Healthcare Provider, Patient 3, Stage 2 interview)

In some cases, healthcare providers had difficulties assessing the roles of family members in providing care of the patient. Culturally shaped gender roles and importance of maintaining care within the context of the family emerged in several cases. In one case where the healthcare provider described her perception that the patient's adolescent daughter had taken a major role in providing care and a family preference that social support came from within the family,

> I think (daughter) had helped her mum so much in the earlier stages – helping her managing her menstruation, showering, and everything was so… it's such a lot.
>
> (Healthcare Provider, Patient 4, Stage 1 interview)

However, interviews with the patient showed that she did not think her daughter should take on such responsibilities,

> My daughter was only 12 and I was told you've got family. I said for God's sake, my daughter is only 12. What you want me to do tell her to drop out of school and stay with me all the time?
>
> (Patient 4, Female, Stage 2 interview)

One of the largest sources of missing data in this study was from the perspective of male carers. From the perspectives of the patients and those male carers interviewed, it was often mentioned that male carers faced additional stress in regards to maintaining work. However, reportedly few male carers were offered social support services; only one carer (for Patient 4) had attended a support group for carers.

In one family where the male parent was ill, the healthcare provider expressed concern over what she perceived to be his lack of involvement with his children. The patient, however, described how it was very important for him to spend time with his children before he died,

> The children love me a lot. I love them a lot too… At night we turn the TV off in the drawing room and they come into my room, (wife) goes upstairs the children are with me and we sit and watch TV together for as long as I

> will allow them…How involved they are with me, people just can't see, I mean when (wife) goes away for a few hours, they're with me and... But if someone comes, I get busy so how can they tell how involved my children are?
>
> (Patient 1, Male, Stage 2 interview)

In summary, some healthcare providers in this study had assumptions that male carers were less likely to provide support than female carers as a result of traditional gender roles and that male patients were distant to their children. Also, some providers assumed that female children were carers which the families did not agree with.

DISCUSSION

Parents expressed sadness over being unable to provide tangible support which was perceived to be necessary for their children having a good childhood despite a parent having a life-limiting illness. Parents with life-limiting illness also perceived that giving their children emotional support was a way for them to maintain their role as a parent. These two themes correspond with previous studies of parenting and children's experiences when a parent has serious illness done in other countries, settings and populations [11 12 13 14 15 16 17 18]. In maintaining their roles as parents and providing emotional support, parents were not as interested in formal support groups for their children as they were in information aiding them to speak themselves to their children about their illness. This is similar to the findings from the study by Turner et al. [14] which found that parents with advanced cancer desired information and resources regarding how they could speak with their children about cancer because they desired to provide emotional support. However, our study also identified social support themes unique to ethnic minorities who had recently migrated, including concerns regarding visa problems for family members to provide care, and geographically distant family members.

Patients and their families were often open to receiving formal tangible support services and sometimes formal emotional support services. However, there were gaps in cultural understanding between healthcare providers and beneficiaries, such as the lack of understanding of children not being able to attend therapy at times of religious services. Some healthcare providers in this study seemed to have preconceived ideas regarding gender roles within Muslim families and availability of social support, thus overestimating the amount of social support females could provide and underestimating males' roles in the family. Whereas health care providers highlighted cultural differences in gender roles and in the importance attached to maintaining care within immediate and extended families patients often expressed unmet needs for formal social support to supplement the support given within family settings. Both the actual and potential roles of male carers were difficult to assess in cross-cultural encounters between families and healthcare providers. Additionally, some healthcare providers overestimated the amount of social support female children provided or could provide. As previous studies have found parents wanted to maintain normalcy for their children [11 12 13 14 15 16 17 18] and parents in this study explicitly did not want their children to take on the bulk of their care.

In a similar study done in England, Katbamna [29] points out that the most vulnerable group to have their support needs neglected is young female carers living in nuclear families because healthcare providers and family members may not acknowledge their need for support. A study by Llacer et al. [35] found that recent arrival may limit the ability for female migrants to develop both social support networks, and achieve important skills such as language or driving. This study had similar findings, for example, transportation needs were consistently highlighted but were the most limited in families where the female carer had recently arrived to the United Kingdom.

Also consistent with the study presented here, another study found that male carers felt that healthcare professionals did not acknowledge their concerns or assumed they were not part of care [25]. In this study, male carers often struggled to be both the primary carer and provider for their family. Some male carers greatly reduced their hours at work or took on the role as a full time carer. However, in our study only one male carer mentioned being offered formal emotional support services.

It was evident that the availability of informal social support networks was inconsistent meaning that friends and family members were not consistently available, either time-wise or geographically, to provide support. This was also found in a study conducted by Kristiansen et al. [5] where social networks of migrants were perceived to be geographically dispersed and thus unavailable in the context of life-limiting illness. Some participants in our study expressed a desire to bring family members from another country to aid with daily life or provide emotional support. Given that informal support networks were inconsistently available, the majority of the social support for the patient fell mostly upon the spouse or primary carer.

The ability to provide culturally competent care has become a common requirement for palliative care providers due to increased ethnic diversity in many European countries [36 37 38]. However, providers may at times have a lack of insight into how culture shapes understandings and responses to death and dying, and how to assess psychosocial needs among different ethnic minority groups [36 37 38 39]. Moreover, healthcare providers may be in fear of being insulting or insensitive [36 37]. Overall, it has been found that health care providers providing palliative care services often do not have the necessary training to provide culturally competent care for patients or understand the complex relationship between culture and health [36 37 38 39].

Patients and healthcare providers had differing understandings of the amount of social support provided by family members. For example, it has been observed that healthcare providers often assume that South Asian Muslim families would prefer to 'look after their own' whereas when British Muslims where questioned, they felt that family structure were changing [36]. Additionally, healthcare providers in ours study expressed curiosity regarding the amount of support patients received from religious communities and/or religious leaders. Yet, among the patients, religious community members and/or leaders were not perceived to be sources of social support. As reported in the original study for which these data were gathered, some participants actually withdrew from their religious communities due to perceived stigmatisation [31]. While religious beliefs have been reported to serve as an important coping mechanism for South Asian Muslims with life-limiting illness [31], religious leaders, imams, were not described as a consistent source of social support for parents of young children.

Methodological considerations

This analysis is a secondary analysis and while respectability of a secondary analysis of qualitative data is growing [40] it is not without its limitations. In this secondary analysis the first author did not conduct the interviews and therefore had limited opportunity to gain a sense of the context of participants' lives. Moreover, the lead researcher is not of the same ethnic background or resides in Scotland. Thus a large amount of reflexivity in the analysis was required as well as discussion with co-authors who performed the interviews. There are, however, benefits to having an outsider perspective. In Interpretative Phenomenological Analysis, pre-understanding must be bracketed or put aside in order to allow the text speak for itself [32]. The researcher came to this study with limited pre-understanding and therefore was able to perform the analysis solely on the text first and then later oscillating between theories of social support, previous research and the data. While there are limitations to a secondary analysis there are also strengths. A secondary analysis allows researchers to view the data through different perspective and allowed the researcher to focus on themes related to social support.

Participants were identified through health and social care workers, community leaders and personal contacts. These sources, in themselves, are forms of formal social support networks. Hence, some of the most vulnerable or isolated persons are likely not included in this study. The use of multiple perspectives strengthened the understanding of the individual experience of the patient as well as exploring different perspectives of the patients, the carers (informal social support) and healthcare providers (formal social support).

Study implications

The reasons for and timing of migration may influence the availability of social support [35]. Themes such as inconsistent informal social support networks or transportation difficulty were often due to timing of migration as migration often leads to dispersed social networks expanding across national borders. In this study, some participants had been born and raised in Scotland and others had arrived to Scotland within 1-12 years of the study date. Therefore, while the majority of support fell on the spouse as the primary carer, patients had varying amounts of extended family available to provide support. The ability to uphold important aspects of the parenting role is furthermore clearly dependant on the type of illness, its' severity and the types of treatments and/or palliative care that patients are offered [41]. Further research is needed in order to understand the influence of these factors on the support needs among ethnic minority parents at the end of life. Studies exploring the experiences of children in families affected by life-limiting illness are needed in order to identify the future support needs of children prior to the death of the parent.

Culture is dynamic and changing and migration often accelerates dynamic changes to culture[36]. While all patients were of South Asian origin, it is important to acknowledge the diversity within the category of 'South Asia' which encompasses a very diverse group of patients and families with varying resources and vulnerabilities [41]. Within the patients interviewed there were patients who had recently migrated and patients who were born and raised in the UK, carers who had migrated to the UK and one carer who is white Scottish. Moreover, participants in the study were from various regions of India and Pakistan. Recognizing how this diversity shapes the experiences of support needs in individual patients is important in order to avoid drawing broad generalizations. In addition, some of our findings underscore the commonalities in psychosocial needs at the end of life across different ethnic groups. For example, and as previously discussed, studies have found that parents with life-limiting illness in general desire to provide tangible and emotional support for their children to maintain normalcy for as long as possible. In our study, culture, migration, gender and socioeconomic position were factors that shaped the expression of this desire to maintain parental support roles despite disabling illness, but the importance of holding on to normality and the experience of need for support in doing so are most likely not confined to ethnic minority groups. To further understand how needs for social support are shaped by cultural factors, including expectations tied to gender roles, the role of ethnic minority status, and the changes occurring with time spend in the post-migration environment, comparisons between longitudinal studies conducted among different ethnic groups are needed [41 42]. Having this insight would help in understanding how to adjust care to meet the specific needs among groups at risk of being inadequately supported in palliative care.

CONCLUSIONS

South Asian Muslim parents of young children with life-limiting illness experienced both informal and formal social support needs in maintaining their role as a parent. Implications for practice include the need for greater awareness by healthcare providers of tangible and emotional social support needs of ethnic minority and migrant parents with life-limiting illnesses. Healthcare providers and other professionals involved in delivery of palliative and supportive care for ethnic diverse populations should more systematically assess both support needs and available informal and formal sources of support that may help families inflicted with life-limiting illness. Support for carers is important and should encompass both male and female carers.. Formal social support services should aim at helping parents to provide services such as transportation for their children and how to talk to children about their illness and death. Finally, future research is needed in order to understand the influence of the timing of migration on the needs for and access to social support services among parents with life-limiting illness representing diverse ethnic groups.

Table 1: PARTICIPANT CHARACTERISTICS

Participant	Gender	Timing of Interview **	Nominated Carer Interviewed	Gender of Carer	Timing of Carer Interview**	Number of children under 18	Home Structure	Immigration Status	Nominated Healthcare Professional	Timing of Healthcare Professional Interviews**
P1	M	Stage 1*-2 Deceased	Spouse	F	Stage 1* Post-Bereavement	3-4	Nuclear Family	Asylum Seeker	Social Worker Palliative Care Specialist	Stage 1, 2 and post-bereavement
P2	M	Stage 1 Deceased	Spouse	F	Stage 1*	1-2	Nuclear Family	UK Citizen	General Practitioner	Stage 1 Post-Bereavement
P3	F	Stage 1,2,3	None	N/A	N/A	2-3	Nuclear Family	UK Citizen	Oncologist	Stages 1-3
P4	F	Stage 1,2,3,	Spouse	M	Declined	2-3	Nuclear Family	UK Citizen	Occupational Therapist	Stage 1
P5	F	Stage 1*,2,3	Spouse	M	Stage 1*	3-4	Nuclear Family	UK Citizen	Social Worker	Stage 1
P13	M	Stage 1*, 2*, 3*	Spouse	F	Stage 1*, 2*, 3*	3-4	Nuclear Family	UK Citizen	Oncologist	Stage 3
P20	M	Stage 1* Deceased	Spouse	F	Stage 1* Post-Bereavement	4-5	Nuclear Family	UK Citizen	Palliative Care Nurse Specialist	Stage 1
P25	F	Stage 1, 2, 3	None	N/A	N/A	2-4	Nuclear Family	UK Citizen	General Practitioner	Stage 2

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CONTRIBUTOR STATEMENT

AS conceived the study and all grant holders developed the design. TI and AW collected the data. This secondary analysis of data was conducted by EMG, with support from all authors. This paper was drafted by EMG, and revised and edited by all authors. EMG and AS are guarantors.

COMPETING INTERESTS

None declared.

ETHICAL APPROVAL

Ethical approval was given by the Lothian County board of Ethics (Scotland).

DATA SHARING STATEMENT

There is no unpublished data from the study

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Laboratory test ordering and results management systems: a qualitative study of safety risks identified by administrators in general practice

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ABSTRACT

Objective

To explore experiences and perceptions of frontline administrators involved in the systems-based management of laboratory test ordering and results handling in general medical practice.

Design

Qualitative using focus group interviews

Setting

West of Scotland general medical practices in three NHS (National Health Service) territorial board areas

Participants

Convenience samples of administrators (receptionists, health care assistants and phlebotomists).

Methods

Transcript data were subjected to content analysis

Results

A total of 40 administrative staff was recruited. Four key themes emerged: 1. System variations and weaknesses (e.g. lack of a tracking process is a known risk that needs to be addressed). 2. Doctor to administrator communication (e.g. unclear information can lead to emotional impacts and additional workload). 3. Informing patients of tests results (e.g. levels of anxiety and uncertainty are experienced by administrators influenced by experience and test result outcome) and 4. Patient follow-up and confidentiality (e.g. maintaining confidentiality in a busy reception area can be challenging. The key findings were explained in terms of sociotechnical systems theory.

Conclusions

The study further confirms the safety-related problems associated with results handling systems and adds to our knowledge of the communication and psychosocial issues that can affect the health and well-being of staff and patients alike. However, opportunities exist for practices to identify barriers to safe care, and plan and implement system improvements to accommodate or mitigate the potential for human error in this complex area.

Keywords: patient safety, risk, test results, human factors, systems thinking, receptionists, primary care

ARTICLE SUMMARY

Article focus

Exploration of general practice administrative staff experiences and perceptions of workplace systems for managing laboratory test results, with a focus on risks and patient safety

Key messages

- Systems for tracking and reconciling laboratory tests ordered with results received are variable, problematic and require improvement
- Communications from doctors to administrators can lack clarity, causing frustration and unnecessary workload
- Maintaining patient confidentiality in busy general practice reception areas can be challenging.
- Dealing with patients’ reactions to test results can be emotionally demanding and potentially awkward for administrators.

Strengths and limitations of this study

- The study involved a number of frontline administrators from a large range of general practices in different geographical areas
- Qualitative methods were used with a key workforce group to elicit a more in-depth understanding of this complex area of practice

- The **convenience sample is a limitation** and NHS Board areas selected do not reflect the diversity of existing results handling clinical information systems used across Scottish general practice

INTRODUCTION

Workplace systems for managing laboratory test ordering and results handling in primary care are known to be variable, often ineffective and unsafe [1-4]. However, related research to quantify risks and explore patient safety issues appears to be non-existent in the United Kingdom (UK) and wider Europe, although a very limited number of North American and Australasian studies are published [3-4, 5-10]. Arguably this research deficit is a symptom of low levels of interest from policy makers on understanding and resolving patient safety concerns in primary care compared with acute hospitals, although recent UK and European initiatives are encouraging [11-12].

For patients and their relatives, poor test result handling systems may lead to avoidable harm and distress, delayed treatments, unsatisfactory care experiences, and the inconvenience of additional appointments to repeat blood tests or make complaints (1-2). For general practitioners (GPs), missed results and poor test follow-up can lead to delayed clinical judgements on diagnostic and treatment decisions, thereby limiting therapeutic options and potentially impacting on patient safety (3-4). The implications may include formal complaints by patients, loss of trust in the doctor-patient relationship, litigation claims for financial compensation and licensure sanctions by medical regulators (9, 13). At the system level, it is evident that many practices do not have adequate processes for systematically tracking test requests, recording test results (both clinically abnormal and normal), and confirming if follow-up action has taken place before results reports are filed or patients are notified (5-7).

In the UK, and elsewhere, primary care based administrators (most commonly frontline receptionists) work in a demanding and complex role that involves communicating with patients and performing a variety of office duties, many of which have safety importance [14-15]. Tasks undertaken include preparing repeat prescriptions, handling laboratory test results, deciding upon the urgency of home and surgery appointments, controlling patient flow to doctors, making hospital appointments and typing referral letters [14-15]. Often there is a feeling that the duties performed are not appreciated or fully understood by doctors or patients (16)

The involvement of primary care administrators in health services research, particularly with a focus on safety and improvement appears very limited, with a significant proportion of studies undertaken over a decade ago. Examples include capturing perceptions, feelings and experiences related to: work roles and in-service training (14-16); influencing access and continuity of care (17); risks and effects of violence, and impacts on psychological well-being and work performance and satisfaction (18-20); improving communication and providing support to enhance clinical care quality (21); and perceptions of how medication errors can occur (22).

Given the evidence of system failings and patient harm, and the pivotal work role played by this key group, administrators may have important insights into what can go wrong in this area which clearly merits in-depth study. The aim of this study, therefore, was to explore the experiences and perceptions of frontline primary care administrators directly involved in the systems-based management of laboratory test ordering and results handling, with a particular focus on identifying risks that may impact on patient safety and other relevant quality of care issues.

METHODS

This qualitative research was undertaken as part of a wider European study to identify, synthesise and integrate a range of evidence based sources of safety-critical issues affecting laboratory test ordering and systems-based results management in primary care. The overall purpose was to develop 'good practice' guidance in this area and build consensus in the UK context and then on a wider European level (23).

Participants and sampling

We contacted via email all general practice managers in three west of Scotland NHS Boards in September 2012 to ask them to invite (on our behalf) representatives from their administrative staff (e.g. receptionists, health care assistants, phlebotomists) to voluntarily attend focus groups on pre-arranged dates. NHS boards were selected on the basis that they had a geographical mix (urban, rural and mixed) of practices and were, therefore, more likely to have different systems for managing results (e.g. mostly computer based, paper-based or mixed computerised and paper systems), which we judged important in reflecting and influencing the types of patient safety risks faced by diverse practices. A convenience sampling strategy was decided upon because of the limitations of purposively selecting participants caused by the time-limited nature of the study and the pre-arranged interview dates.

Focus group interviews

Five group interviews were held in west of Scotland health care settings in Glasgow (n=3), Motherwell (n=1) and Kilmarnock (n=1). LH moderated each session and assisted the discussion with the aid of a brief topic guide (Box 1), informed by issues previously raised in the literature (3, 5, 8). Participants were asked to view ‘patient safety’ pragmatically in terms of results handling incidents, or potential incidents, which they would not like to happen to themselves or relatives. They were encouraged to speak freely about their experiences and perceptions of all aspects of the results management systems in their practices. Assurances were given that their views would be treated in the strictest confidence and that they would remain anonymous on transcripts. Sessions lasted between 45 and 70 minutes and were digitally recorded and transcribed with permission. Contemporaneous field notes were also taken.

Data analysis

The transcripts were subjected to conventional qualitative content analysis [24] - to provide knowledge and understanding of the phenomenon under study [25] - on an iterative basis as data collection progressed. Data were systematically coded, categorised and initial themes identified by LH. Cross-checking of data categories and themes with the transcripts was undertaken by PB to enhance validity. Categories and themes were modified and reduced by merging and linking them after joint discussion between both researchers, with disagreements resolved by consensus. To validate further, we emailed a summary of the draft findings to study participants for critical comment and input, but none provided feedback.

RESULTS

All 40 staff who agreed to participate from the three discrete Health Board regions approached, attended the five focus group interviews (Table 1). We achieved data saturation by the fourth focus group, with the final group interview affirming this. Almost all participants were female (n=39, 97.5%), with 25 based in urban practices, nine from semi-rural practices and six from rural practices.

Four principal themes were identified:

1. System variations and weaknesses
2. Doctor to administrator communication
3. Informing patients of test results
4. Patient follow-up and confidentiality

System variation and weaknesses

A 'grey area' of mixed computerised and manual processes that underpinned results handling systems was described. For some, particular importance was placed on manually recording all blood tests ordered and reconciling the results when received from the laboratory. For others, the high volume of tests ordered made the workload involved in reconciling tests ordered with results received 'impossible' and this impacted on what was communicated to patients, while there was also a reliance on patients to contact the practice for test results .

Many participants reported using both electronic and paper copy results systems for the same patients to act as a safeguard because of a range of perceived technical and user problems receiving and managing results electronically. The paper copies were also reviewed and then scanned into patients' records and archived. This was viewed as task duplication and a source of frustration because of the reconciliation workload involved. There was consensus that the lack of a tracking system for results handling is a known risk and ongoing concern and needs to be addressed and improved within many GP practices. It was the experience of some participants, that if a patient fails to contact the practice, even if the result is abnormal, they might never receive this information or it will only come to light if they attend in future with a related or different problem.

> *"…there could be maybe three or four bloods done and you get two results and you will be relaying the information* [that] *your results were normal and one or two have still to follow…"* (Focus Group 2)
>
> *"…it is coded when they have had a sample taken and every day we run a search five days before to see what bloods were taken and make sure they have all come back."* (Focus Group 3)
>
> *"…we check that every day we have a blood book… they go through the whole lot and check when it [the result] comes back in".* (Focus Group 1)
>
> *"…putting the EMISS* [information system] *results into the patient's notes and then the Docman results is going into the patient's notes…defeating the purpose".* (Focus Group 1)
>
> *"…the onus [is] always on the patient because they are asked to phone back in to get their results…"* (Focus Group 3)
>
> *"…someone is phoning and we are telling them (the result) is normal and the next day two more come in and there is something wrong with them or one went missing, if that patient didn't phone in for the result and that result has gone missing, if the blood has gone missing before it has even got to the lab, or there has been some sort of lack of communication with the bloods they wouldn't know if it is back or not if the patient phones up and asks for the result and then we would chase the lab and unfortunately the patient doesn't know what bloods are being taken".* (Focus Group 4)

Communication between doctor and administrator

Mixed feelings of anxiety, frustration, pressure or awkwardness emerged often caused by limited, unclear and ambiguous test result communications by doctors which would then require further clarification. For many, comments written by doctors on results reports for staff to relay to patients sometimes "*don't make any sense*". Some participants also felt inhibited in what they can say to patients, particularly when advised by doctors never to communicate anything other than what is in their messages. Contacting doctors to clarify the meaning of the message and also ask the patient to telephone back added to workload and inefficiency. Approaching some doctors for clarity could be daunting for some participants in these situations because they may exhibit discourteous behaviours.

A whole series of common terms and words routinely used by doctors in communicating results were described and debated – *'satisfactory', 'acceptable', 'normal', 'slightly abnormal', 'no action required'* – which both staff and patients struggled to make sense of depending on the clinical context, and particularly where the patient queries the result or reacts negatively. For some, this was compounded by a sense of uncertainty in their practices that they are not always doing the same action when communicating results. This limited understanding combined with incomplete information made available to staff impacts on communication difficulties with patients.

> *"…he might bite my head off…it depends which GP it is as well…some are more approachable".* (Focus Group 5)
>
> *"…a result will say abnormal but it might not necessarily be abnormal to the doctor or where it's maybe satisfactory compared to last month's bloods but it doesn't mean they are normal…".* (Focus Group 2)
>
> *"I feel as if they don't really give us enough information to pass it onto the patient…sometimes the doctors are not very detailed"* (Focus Group 1)

Informing patients of test results

Differences were apparent in how participants were instructed to inform patients of blood test results and who undertook this task. Some were only ‘permitted’ to communicate to patients exactly what the doctor had written in the results report, while others were given less guidance on this issue. This was exemplified in one group discussion around Cholesterol results which highlighted how some were permitted to pass on actual Cholesterol levels while others were instructed never to do this.

Participants had mixed feelings about notifying patients of blood test results. Many described some level of anxiety and uncertainty when communicating test results, with a few describing the process as ‘scary’ or ‘intimidating’. This was especially so when they were new in post, as they were nervous and unsure if they were relaying the correct information, with some suggesting they tried to avoid this task. Some anxiety related to using unfamiliar medical terminology that has no meaning for them. For some the process is straight-forward and unchallenging most of the time, while it was stressful for others but this lessens to some extent as confidence grows with experience. However, this depended on the actual result and what they were instructed to tell the patient, with most agreeing the process was difficult when communicating ‘bad news’.

Dealing with a patient’s expectations and reactions when informed of a test result was also a challenge, with many participants’ feeling pressurised into engaging in further discussions. When informed their results are normal, patients can sometimes appear to be “unhappy”, “disappointed”, or even “astonished” that this is the case given their perceived clinical condition, leading them to seek clarification, double-checking and re-testing. Some patients also assumed that administrative staff are able to interpret the result and provide further clarity. When informed a letter is to be sent to them, or if asked to return for a repeat blood test, patients may also become visibly anxious or agitated inducing stress and discomfort in staff who felt very limited and inadequate in terms of providing reassurance.

There was consensus that a clinician would ideally be the most appropriate person to communicate test results to reassure patients, provide further explanation and enhance safety. However, it was acknowledged by most that they have a job responsibility to perform this task and that in most cases test results are normal, while many of the complicated abnormal results and associated emotional impacts are usually, but not always, handled by practice clinicians.

Many often felt pressured to communicate to patients more than they are comfortable with, with some suggesting that giving results should not be part of their role because they are not clinically trained. For some, they feel at times *"pushed"* by the patient to give them more information, however most recognise this as potentially *"dangerous"* in terms of giving out inappropriate information and perhaps incurring the wrath of the doctors.

> *"I don't even know what I am talking about and I am trying to explain* [test results] *to somebody".* (Focus Group 2)
>
> *"…when I started giving out the results I was terrified I didn't relish the prospect"* (Focus Group 2)
>
> *"I always feel a wee bit anxious when I am giving out these kind of results because for one you are not sure if what you are telling them is the right thing and you don't know how they are going to react"* (Focus Group 3)

> *"…we give out, for example, urine results although the GP's not seen them because it is absolutely spot on clear, we always say doctor hasn't seen this result yet it is a provisional result, should there be anything that the Doctor needs to talk to you about then we will get back to you, I put on that result 'patient informed negative for infection trust this was ok' that is my comment it goes back to the GP, it is always seen".* (Focus Group 3)

> *"I think a nurse or someone with some clinical background should be dealing with it".* (Focus Group 2)

> *"I find it hard when they are ringing for results and you need to make them an appointment and they go into panic at the end of the phone and you can't give them any more information, I am not medically trained I can't tell you then you have got nobody to ring them back".* (Focus Group 1)

> "…[communicating]*a bad result…just as a human being there is something you are seeing* [the result] *before that patient knows*." (Focus Group 5)

> *"You don't want to get involved in conversations like that* [going into detail about results], *they just go wrong*" (Focus Group 5)

Follow-up and confidentiality

Failure to contact patients despite making numerous telephone calls and sending letters was a continual source of frustration, while patients failing to make contact for test results despite being instructed to at previous appointments emerged as key follow-up issues. Protecting patient confidentiality was a problematic area of practice, particularly in face-to-situations in busy reception areas which lacked private spaces. Some participants would refuse to give results over the telephone if they were unable to verify the caller's identity, while others admitted to deviating from protocols by communicating results if they personally knew the patient or a relative, particularly where the patient was ill or had a disability. Caller identification systems also caused problems for staff and patients in circumstances where the practice number shows up on the patient's home telephone system and they subsequently telephoned back, but practice staff are not immediately aware who made contact with the patient and why, which causes additional delays and workload to resolve the issue.

The use of signed authorisation forms by the patient and automatic systems alerts to authorise permission to another person (e.g. partner) to receive a result were also in common usage. However some practice policies insisted on seeing and receiving patients' authorisation in person, particularly where the patient did not speak English.

The practices of many participants had an age-cut off for parents who may telephone to receive their child's results on their behalf, which can cause upset and anger when administrative staff refuse to comply with parents' requests. When unable to contact patients by telephone leaving the practice contact number and not explaining who is telephoning and why, was a common policy for some. Others would not leave any message unless the patient had explicitly agreed to this. Some participants described potential breach of confidentiality incidents where colleagues had telephoned patients and left voicemail messages on home telephones explaining who was calling and to return the call to receive their blood test results.

Mixed work practices emerged over where and how to communicate test results with many participants favouring face-face contact rather performing this task over the telephone, although some reported that patients can dislike telephone contact. Maintaining confidentiality at the reception desk was a major concern, with some practices preferring not to give out results here because it was difficult to maintain privacy, particularly when very busy. Some participants agreed the onus was on the patient in this situation and that if they choose to ask for test results in an area where they could potentially be over-heard then they were happy to communicate them, although in most cases patients are being informed that the result is normal or to telephone back.

> *"…a lot of them just don't phone back, you're maybe getting them three months down the line saying, I had bloods done".* (Focus Group 2)

> *"…there are lots of issues at the front desk that can be an absolute nightmare for us…it is difficult you have got a crowd at the door and someone is wanting to get their [test] results".* (Focus Group 4)

DISCUSSION

The main safety risks experienced and perceived by GP administrators in this study covered a wide range of system level weaknesses, doctor-administrator-patient communication issues, maintaining patient confidentiality, following-up patients and coping with their reactions to, and expectations of, blood test results. Participants' accounts of systems, communication and psychosocial problems expose the potential for error, inefficiencies and frustrations associated with handling test results.

Strengths and limitations

The use of focus groups enabled us to explore this under-studied issue in greater depth with an important part of the relevant workforce than we would have done, for example, using a questionnaire survey. All participants who volunteered a willingness to participate actually attended the group interviews which may be an acknowledgement that this is an issue of high interest. The discussions were lively and we were satisfied that every participant was able to make an adequate contribution. Limitations include the fact that **a convenience sample was used, whereas a purposively selected sample may have provided greater insights into relevant issues amongst a more diverse range of staff and practices**.

Selection bias may have been introduced due to a reliance on practice managers helping to recruit study participants from their own practices. This is because in the UK there is no other way of making direct contact with GP administrators as external health authorities do not hold personal database records of these staff groups in the same way as other (clinical) groups. We were also unable to link participants' views and experiences with the demographics of the practices in which they were based and the systems used, **nor did we collect data on participants' age, gender or years of experience.** Other limitations are that some practices use only nurses to communicate test results to patients while practices in geographical areas not covered use full electronic tracking systems for results handling. Addressing these issues would have enhanced the robustness of the study and the strength of our findings, which should be viewed with some caution given this context.

The reported weaknesses of practice systems is comparable with previous research which found that participants experienced multiple problems in the different process steps involved in results handling, with inadequate systems and lack of standardisation being identified as contributory factors [5, 26). Additionally, difficulties arising in the clarity of verbal and written communication between doctors and others, including the potential for perceived disrespect or rudeness [27], are a recognised hierarchal problem which may also impact on safety in the workplace (3, 28). In this regard, there are recommendations for doctors to develop a greater understanding of the administrator's work role (16, 20). Although administrator-patient communication has been the subject of limited research previously – mainly focused on the administrator as a barrier to accessing care – our findings suggest that some administrators struggle with the inter-personal and emotional demands of informing patients of test results and handling follow-up queries. Dealing with patients' sometimes difficult expectations and reactions, and feeling caught between the demands of doctors and patients are previously reported as workplace stressors for administrators in primary care (16). Finally, the issue of patient confidentially being breached in the reception waiting area is a known significant event [1], but can sometimes be difficult to mitigate given the lack of private space availability afforded in the design of healthcare facilities and the attitudes of staff and patients towards confidentiality (29-30)

One way to interpret and explain the findings and consider the wider issue of test result handling at the practice level is to understand the workplace in terms of sociotechnical systems theory, which is highly influential in human factors science and application (30-32). In essence this suggests that the success of any workplace system or technology is strongly interdependent on the social relational contexts of work organisation, rather than just on the systems or technology itself. There is a growing interest in the need for healthcare professionals to be trained to understand and implement human factors and ergonomic principles in the workplace [23, 33]. Taking a systems approach to designing job tasks and work processes to accommodate human capabilities and limitations, and therefore minimise the risk of errors, is an important element of this discipline [33-35]. There appears to be a clear alignment between many of the social and technical interactions and interdependencies of test results handling systems uncovered in this study (and the wider literature) that would benefit from a human factors approach.

Patient safety research is still in its infancy, particularly in primary care [11-12, 36]. Although we know from limited taxonomy studies undertaken that test results handling is a major issue [1-2, 37-42], we need a more in-depth understanding of the related human-task-system interactions and socio-technical risks inherent in the practice systems we design if potential solutions to problems are to be realised [43]. Involving key staff groups such as administrators and using qualitative research methods to explore these issues is, therefore, paramount to advancing knowledge about practice culture (e.g. leadership behaviours and commitment to improving safety), psychosocial issues (e.g. staff motivation and input to relevant decision-making) and technical difficulties (e.g. reliability of test result handling processes and information technology). Arguably all will have to be addressed before we can begin to make progress in re-designing and evaluating improved test result handling systems to minimise errors and patient harm.

CONCLUSION

The study further confirms the safety-related problems associated with results handling systems in primary care and add to our knowledge of the communication and psychosocial issues that can surface at the doctor-administrator and administrator-patient levels, potentially affecting the health and well-being of staff and patients alike. However, they provide an opportunity for practices to identify barriers to safe care, and plan and implement system improvements to accommodate or mitigate the potential for human error in this complex area. A potential learning need to develop educational solutions for the primary care workforce to strengthen human error knowledge, whole system awareness, team working and internal communications is also apparent.

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Contributors

PB conceived the study idea, acquired funding, assisted with the study design, data analysis and interpretation, and the drafting and critical revision of the manuscript. LH assisted with the study design, led the data collection, analysis and interpretation and helped draft the manuscript. JM contributed to the drafting and critical revision of the manuscript. All the authors have approved the manuscript.

Competing interests

None.

Ethical approval

This study was pre-screened by the west of Scotland research ethics committee but was judged to be service evaluation.

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Box 1: Focus Group Topic Guide [3, 5, 8]

Study Aim:

To explore experiences and perceptions of frontline administrative staff directly involved in the systems-based management of laboratory test ordering and results handling in general medical practice.

Topic Guide Questions

Focus group participants were asked:

- about the main problems and frustrations with their practice systems
- how these might impact on patient care and safety
- how they feel about their job role and their interactions with other staff groups
- how they feel about their job role and their interactions with patients

Table 1: Details of Focus Groups and Study Participants

Focus Group	Location & NHS Board area	Receptionists (n)	Health Care Assistants (n)	Phlebotomists (Main role) (n)	Total Participants (n)
Focus group 1	Glasgow, NHS Greater Glasgow & Clyde	5	1	0	6
Focus group 2	Glasgow, NHS Greater Glasgow & Clyde	7	1	2	10
Focus group 3	Glasgow, NHS Greater Glasgow & Clyde	5	2	2	9
Focus group 4	Motherwell, NHS Lanarkshire	6	0	0	6
Focus group 5	Kilmarnock, NHS Ayrshire	7	2	0	9

*Takes blood samples from patients as directed by clinicians and completes related administrative tasks

Areas for Practice Improvement?

Practices may wish to reflect on whether acting on the following issues may improve the safety of their results handling systems:

Training and support for administrative staff on the safe communication of test results to patients and in dealing with reactions and expectations.

Training and support for all staff groups on the basic principles of whole systems thinking and human factors practices

A standardised process for tracking and reconciling tests ordered with results received that is co-designed, fully understood and used by all relevant staff.

A standardised process for following-up patients with clinically significant abnormal results in order to prevent a reliance on the patient to make contact with the practice.

A standardised set of words, terms and phrases - agreed between clinicians and administrators - to enable administrators to communicate and explain common test results to patients using language that is clear, unambiguous and promotes patient safety.

A standardised process that guides how and how often practices attempt to contact patients who require follow-up that is fair and reasonable from a medico-legal perspective.

A standardised process that feasibly minimises the risk of breaching confidentiality by staff when communicating tests results to patients face-to-face or over the telephone (including potential redesign of working areas to enhance privacy).

A commitment by doctors and nurses to ‘shadow’ administrative staff for a short period of time to acquire a better understanding of their job roles and tasks undertaken, and related difficulties and anxieties.