

Experiences of a Novel Integrated Service for Older Adults at Risk of Frailty: A Qualitative Study

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Imogen Wilson, MSc¹, Blessing O Ukoha-kalu, PhD¹,
Mabel Okoeki, PhD¹, Joseph Clark, PhD¹, Jason W Boland, PhD¹,
Sophie Pask, MSc¹, Ugochinyere Nwulu, MSc¹,
Helene Elliott-Button, PhD¹, Anna Folwell, MBChB²,
Miriam J Johnson, MD¹ , Daniel Harman, MBChB², and
Fliss EM Murtagh, PhD¹ 

Abstract

The UK has a significant and growing population of older adults with frailty and complex healthcare needs, necessitating innovative care solutions. This study aimed to explore patients' and carers' experiences of a novel integrated service that was set up to address the increasing healthcare needs of older people living with frailty. A qualitative study that combined free-text survey questions with in-depth interviews. This study is part of a larger non-randomized trial of the service, with evaluation of wellbeing and quality of life at baseline, 2 to 4 weeks, and 10 to 14 weeks. Patients (aged 65 and above) with an electronic Frailty Index in the severe range and their informal family carers participated in this study. Data were collected between April 2019 and March 2020. Free text survey responses and interview data were subjected to reflexive thematic analyses. Four themes were generated: the overall experience of the service; interactions within the service; treatment and interventions; and outcomes due to the service. Most participants wanted further follow-up and more extensive integration with other services. Most participants described their overall experience positively, especially the available time to address their full range of concerns, but opportunities to integrate the service more fully and to extend follow-up remain.

Keywords

qualitative research, frailty, older people, survey, integrated care

Introduction

Providing primary and community healthcare to elderly individuals is becoming increasingly difficult due to the growing number of older people worldwide, projected to reach 2.1 billion by 2050.¹ In countries with ageing populations, frailty—defined as a group vulnerable to adverse outcomes²—is becoming more common, as a consequence of the changing age distribution in the population.³ In the United Kingdom, the prevalence of frailty among people aged 65 years and above is 10%, increasing to 25% to 50% among those 85 years and over.⁴

Frail people are more likely to experience negative health outcomes such as hospital or care home admission, disability, mortality, and the onset or progression of several chronic diseases.⁵ Health and social care services are increasingly focused on enabling older people with frailty to live

independently in the community and avoid or delay hospitalization.⁶ In addition, the necessity for healthcare reform to accommodate the increase and complexity of these needs has become more apparent.⁷

Integrated health services for individuals with multiple health conditions strive to improve care access, quality, patient-centeredness, outcomes, and cost-effectiveness.⁸ These services are based on a holistic perspective of all the

¹ Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull, Hull, UK

² City Health Care Partnership, Hull, UK

Corresponding Author:

Fliss EM Murtagh, Allam Medical Building, Hull York Medical School, University of Hull, Hull, UK.

Email: fliss.murtagh@hyms.ac.uk



patient's health and social care needs and strive to provide proactive, personalized, and multidisciplinary care in different settings and for different levels of care.⁹ There is some evidence that integrated care for older people with frailty provides these advantages,¹⁰ where the provision of multidisciplinary team-led care enables patients to be more active participants in their care.¹¹ A recent study showed that the novel integrated care service improves the well-being and quality of life of older people with frailty within 2 to 4 weeks and sustains the improvement for up to 3 months.¹² There is limited evidence on the valued components of integrated care for older individuals living with frailty and how it should be structured, as well as limited knowledge of their experiences with integrated services.

The objective of this study was to explore patients' and carers' experiences of a novel integrated care service aimed at proactively supporting older people living with frailty, to better understand if and how the new service was regarded by patients and how it might be improved.

Methods

Study Design and Participants

This was a qualitative study, using (i) free text survey questions and (ii) in-depth interviews, with patients and/or family carers attending an integrated care service. In this service, healthcare professionals from various specialties collaborate to provide a holistic and well-coordinated approach to managing a patient's health. This study is part of a larger non-randomized trial of the service, with evaluation of symptoms and quality-of-life at baseline, 2 to 4 weeks, and 10 to 14 weeks.¹² In addition to this trial, an experience survey was conducted, with in-depth interviews with a sample of survey respondents. This paper reports the free-text survey responses and interview findings.

Setting and Service

This study was conducted within a novel integrated care service located in Hull, England, UK. This new integrated care service is described in full elsewhere,¹² but included a comprehensive assessment and care plan provided by a specialized multidisciplinary team, with a free lunch during a 3 to 5 h single appointment.

Eligibility Criteria

Eligible participants in this study were consenting patients receiving the integrated care service, who were aged 65 years of age and above, and were identified to be at risk of severe frailty (electronic frailty index score ≥ 0.36).¹³

Sampling Strategy

Free text data were gathered from the trial intervention group and in-depth interviews were conducted with a subsample

selected based on key neglected symptoms from the main evaluation survey.

Participant Recruitment and Data Collection

At preassessment, the Integrated Care Centre team informed potential participants about the study. The research team then approached interested participants during their Integrated Care Centre appointment to obtain written or witnessed verbal consent. Survey completion and interviews were conducted face-to-face or by phone by a research team member.

All interviews were undertaken between April 2019 and March 2020 and included two questions based on the experience of the novel service with space for free text comments: "How would you define your experience at the centre?" and "What, if anything, could have been done better?" Interview topic guides for the in-depth interviews were developed in relation to the specific symptoms (pain, breathlessness, and unexplained weight loss) from the literature and pretested. Patients' overall experiences, service processes, treatment and interventions, health outcomes, communication, and follow-up services were explored. Interviews were audio-recorded and then transcribed verbatim and anonymized.

Data Analysis

NVivo version 12 software¹⁴ was used to manage the data and to generate a word cloud to represent the frequency of words used by participants to reflect their experience of the service.

Descriptive statistics (frequency, percentage, mean) were applied to the quantitative responses to the experience survey. Both free-text data and interview transcripts were analysed using reflexive thematic analysis.¹⁵ Three members of the research team, working independently, checked the themes and codes. All disagreements were resolved through dialogue with the rest of the research team.

Results

Free text responses to the two survey questions were supplied by 164 (65.6%) of 253 patients who participated in the main trial (intervention arm). Of the 164 survey respondents, 52 patients and 27 informal family carers also provided in-depth interviews, providing 53 interviews overall (some interviews were conducted with both the patient and carer together, as preferred). Table 1 shows the characteristics of patients and carers who participated in the study.

Study Themes

From the analyses of both survey free-text responses and interviews, patients' and carers' experiences concerned 4 main themes: (1) overall experience of the service; (2) interactions within the service; (3) treatment and interventions; (4) outcomes due to the service. Table 2 shows more detail on subthemes.

The organization was commended as “exceptionally good” and the provision of free transportation and lunch were particularly appreciated:

The overall experience was fantastic. They even sorted transportation and provided a meal [Patient, 70, 01/165, White].

Participants reported that the information provided at the centre met most of their concerns:

... I was able to discuss my concerns and how I was feeling. I felt heard. I also feel like most of my health concerns were addressed.... [Patient, 66, 01/100, White].

Theme 2: Interactions Within the Service

Communication before the day. Participants reported being “sceptical,” “anxious,” and “uncertain” about what to expect from the service:

... I was initially sceptical about what to expect and the level of care that I would receive as I felt the invitation had an undertone delivery of bad news... [Patient, 76, 01/038, multiple/mixed ethnic groups].

However, it was thought that developing strategies to outline what to anticipate on the day may help reduce anxiety.

Communication on the day. In the survey, over a third of the participants reported—in response to the question “How would you define your experience at the centre?”—that they felt heard and listened to while at the center. Participants also had the impression that staff paid attention, explained, and were interested in what they had to say:

I felt cared for and listened to by both the centre staff and clinical staff. It was nothing like I have ever experienced [Patient, 95, 01/015, White].

In the in-depth interviews, communication was rated as good, with most of the participants reporting that they were listened to, that they were able to express all of their concerns, and that the staff explained things well:

Oh, everybody that spoke to me seemed [like] they wanted to listen to me [Patient, 89, 01/136, Mixed/Multiple ethnic groups].

Time spent at the Centre. In the survey, many participants commented positively on the amount of time spent with staff. They expressed that the time given to them during their appointment allowed them to talk at length about topics they might not otherwise have had the opportunity to discuss:

What I enjoyed most about the visit was the good pace of each session and not feeling rushed ... I was able to talk about all my concerns [Patient, 91, 01/016, White].

While most participants interviewed expressed satisfaction or positive views about the amount of time, they were able to spend with the health professionals, there were divergent views, albeit very few. Just one carer expressed dissatisfaction about her time with a doctor:

I mean when we went to [the] centre, we spent an hour and [a] quarter didn't we? [...] but that was mainly about the medication and the changes and this, that, and that. I mean he never laid a hand on [name of patient] at all he never checked anything [...] [Carer, 87, 01/118, White].

Support at the Centre. In the survey, participants' experiences interacting with staff on their visit were almost always reported as good. Participants described the staff as “kind,” “caring,” “helpful,” “friendly,” “attentive,” and “patient.” They felt that staff treated them with “dignity” and “respect” and made them “feel comfortable”:

They were very patient and had smiles on their face throughout [Patient, 84, 01/128, White].

In the interviews, the staff were described as “marvellous,” “extremely kind,” and “excellent” by participants:

The doctor was lovely [...] All the staff were lovely [Patient, 67, 01/178, White].

Home Visits

In the interviews, participants expressed the joy they had when some of the staff visited them at home to ensure they had all they needed to live independently:

... and some people came to check my rails and bathroom just after I visited the centre. it's amazing ... [Patient, 85, 01/059, White]

Theme 3: Treatment and Interventions

In the survey, participants stated that the service provided them with a wide choice of treatments and interventions. Participants, for example, received medication reviews and subsequent recommendations and a range of assessments, equipment, general support, and advance care planning. Participants noted changes to their existing treatments, many of which had been in place for a long period without being reviewed:

She has always been on painkillers for the 7 years I've known her. She hadn't had a medication review until she came to the center [Carer, 47, 01/003, White].

However, a number of participants were less comfortable with the care planning for the future, especially regarding the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) form, a tool used to promote

advance care planning and individualized recommendations for a person's clinical treatment.¹⁶

My only downside on the day was around the ReSPECT form. I felt uncomfortable as it involved a sensitive issue. I felt like someone on a deathbed asked to write their will. That was the only not-so-pleasant thing about the day [Patient, 74, 01/054, White].

Theme 4: Outcomes due to the Service

Positive health outcomes. In the survey, visits to the centre were reported to have resulted in beneficial health outcomes by most of the participants. No participants reported adverse outcomes. These visits to the centre for the integrated care service left participants feeling "better than they've ever felt" and "the best they've felt in a long time."

In the interviews, participants reported that receiving the novel service resulted in a variety of good health outcomes. As one participant explained how his visit to the center helped his mobility:

... I had my medication reviewed and I also got to see the physiotherapist for my legs. This has improved my walking ... [Patient, 83, 01/184, mixed/multiple ethnic groups]

Follow-up with primary care. In the free text survey, few participants expressed their dissatisfaction with the failure to implement medication modifications recommended at the centre:

I was told changes to my medications will be actioned by my GP, but it has been over 3 weeks since I visited the center [and] I haven't heard anything or received my medication ... I called my pharmacy, they had no clue about what I was on about [Patient, 83, 01/185, mixed/multiple ethnic groups].

In response to the question "What, if anything, could have been done better?", there were a few added suggestions. Some of the participants stated that their family doctor had not implemented recommendations made at the integrated care clinic, implying a need for closer coordination between the centre and their general practice:

I was on digoxin. They [name of center] took me off it [...]. Dr [local GP] says "I don't know why they took you off it" [...]. Well, I felt confused. When I went in the chemist's [...] she said "Why have they taken you off it" [...] [Patient, 82, 01/036, White].

In the interviews, following up on their initial assessment, some participants also related these same reflections of limited follow-up. Participants said the center was supposed to refer them to a service, but they had not heard anything since:

There's something that we've been told we're going to get looked at and it hasn't been followed up [...]. The way I've always looked at it myself [...] is that once you've got this and that done, you're discharged and that's it until the next episode or something happens [Carer, 61, 01/131, White].

Discussion

This qualitative study aimed to explore patients' experiences of a novel integrated care service and to understand how these experiences could be used to refine and improve the model of care provided. Participants highly complimented the person-centered and well-coordinated care of the Integrated Care Centre, including the holistic and integrated approach and active involvement in decision-making processes. The survey reports complimented the service, with very few divergent views, providing valuable insight into if and how an integrated care service of this type is experienced.

First, communication with the staff was nearly universally rated as excellent. Communication is critical for good collaborative practice and has been related to better patient and provider outcomes.¹⁷ Staff were described as compassionate, courteous, and helpful, and they treated patients with respect and dignity, according to our findings, which are consistent with earlier research on patients' experiences with other integrated care teams.^{10,18,19} Second, patients appreciate being treated with dignity, allowed enough time, and being supported, monitored, informed, and encouraged by the staff indicating that how the service is provided is important. Third, patients stated that this service provided holistic care since staff addressed the complete spectrum of their requirements and listened to them. Our findings are consistent with previous work acknowledging the importance of receiving complete attention and being listened to in integrated care settings to feel understood, whatever their concern.²⁰

Some areas for refinement were identified. Patients who participated in this study explained the need for better coordination with and follow-up through other primary and community services. Integration of these services is widely believed to improve patients' experience, quality of life, efficiency, and health outcomes while also lowering costs.¹⁹ Some consider that several service providers will need to combine their efforts in a coordinated manner to meet the varied demands of the growing older population.²¹ Implementing the service's recommendations by physicians in primary care is thought to be a possible way to improve patients' experiences. Patients' positive experiences with integrated care services are highlighted in current evidence, which boosts patient satisfaction.²² Our study found some concerns about follow-up and integration of services. Previous research has revealed that there are barriers within integrated care settings that make multidisciplinary care challenging toward being effective in terms of follow-up care.²³

The split between primary and secondary care, the divide between health and social care, the lack of a single electronic patient record, insufficient communication between services, and healthcare staff's concerns about data security and information sharing are all examples of these barriers.^{23,24}

The pace of each session provided by our integrated care service was well received by the participants; considerable time was allowed for each patient, and this may be an important component of this type of service, especially for older people at risk of frailty, commonly with multiple long-term conditions. Few doctors believe they can offer high-quality, comprehensive care in a regular ten-minute session²⁵ and the current extreme pressures on primary care make delivery of comprehensive primary care difficult.

Strengths and Limitations of the Study

Our findings contribute to the growing body of evidence that supports which aspects of integrated and other care services are positively experienced by the older population living with multiple conditions and frailty,^{26–29} with emphasis on good quality communication, dignity, sufficient time, and a comprehensive multidisciplinary team.

In-depth interviews represent a limited sample and may not be widely representative. The service is based in Hull, UK, where local context and requirements may differ due to the area's deprivation status,³⁰ and the UK health system setting

Research and Clinical Implications

High-quality and skilled communication should be a focus of novel integrated care services, with staff listening and explaining things in a way that patients can comprehend and allowing patients to express all their concerns. Considerations of dignity, allowing enough time, and providing a comprehensive multidisciplinary team have all emerged as important components of such a service, to deliver the optimal experience. These support the NHS long-term plan and the Social Care Act 2014, which aim to improve care and support for older people and other vulnerable populations. The need to ensure adequate follow-up and communication with other primary and community care needs more consideration. Qualitative interviews with patient and professional participants in integrated care settings could be considered in future studies to see how similar services perform detailed assessments and whether patient respondents have similar experiences. More evidence on costeffectiveness and the impact of such a novel integrated care service on patient wellbeing and quality of life is needed.

Conclusion

Our data provide an understanding of patients' experiences of a novel service provided by an Integrated Care Centre and which aspects of these experiences are most important for a

positive experience. Communication with staff, quality of service, and service culture were mostly evaluated as excellent. This novel service was experienced positively by recipients, but opportunities to integrate the service more fully and extend follow-up remain.

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Author Contributions

FEMM, DH, MJJ, and AF devised the study and developed/refined the main conceptual ideas. FEMM and MO led the study protocol development, ethical application, and gaining approval, with input from the whole team. MO, SP, UN, and HE-B undertook recruitment and data collection. JC, MJJ, and JWB provided support for study conduct, data collection, and analyses. IW and FEMM worked on the survey and interview analyses. BOU-K and FEMM drafted the manuscript. All authors helped refine the manuscript and approved the final version.

Declaration of Conflicting Interests

The authors declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: Fliss Murtagh is a UK National Institute for Health and Care Research (NIHR) Senior Investigator. The remaining authors declared no potential conflicts of interests

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Ethics Approval

This study obtained complete ethical approval (IRAS project number 250981, NHS Research Ethics Committee number 18/YH/0470) from the NHS Research Ethics Committee.

Informed Consent

Before having each participant sign the written informed consent, we made sure they read it, understood its contents, and decided they wanted to take part in the study.



Data Availability Statement

The data that support the findings of this study are available from the corresponding author, upon reasonable request.

Statement of Human and Animal Rights

We confirm that all procedures followed the rules outlined in the Declaration of Helsinki.

ORCID iDs

Miriam J Johnson  <https://orcid.org/0000-0001-6204-9158>
 Fliiss EM Murtagh  <https://orcid.org/0000-0003-1289-3726>

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