Improving unpaid carers involvement and experience of the frailty pathway: A pilot study using an Unpaid Carer Experience Measure

Abstract

Purpose: There is a recognised need to involve unpaid carers when the person they care for is being discharged/transferred from hospital. Research indicates often this involvement is overlooked which can delay discharge and impact patient and carer experience. This study aims to improve the involvement and experience of unpaid carers for those patients on the frailty pathway in a UK-based University Health Board hospital.

Design/Methodology/Approach: This action research study was part of a quality improvement initiative. It took an appreciative inquiry approach and employed the Model for Improvement to undertake PDSA (Plan Do Study Act) small tests of change. Improvement tools such as process maps and fishbone diagram were used to define the problem. Baseline patient data were analysed, along with survey data from unpaid carers and ward staff.

Findings: 88 patient records were reviewed and over half of unpaid carers were identified within 12 hours of patient admission. An Unpaid Carer Experience Measure (UCEM) was trialled, 39% of the carers surveyed reported being continually involved in discharge planning. To improve the level of involvement of unpaid carers in the discharge process, staff indicated the need for more training and better communication across the organisation and with key stakeholders.

Originality: Few studies have developed and trialled unpaid carers' experience measures within healthcare settings, especially within discharge planning. There is also a novelty to taking an appreciative inquiry approach to this quality improvement.

Research limitations/implications Further research is needed to test and evaluate the wider use of UCEM.

Keywords: Quality Improvement, involvement, Unpaid carers, Discharge Planning, Frailty Pathway, Experience Measure, Action research, Appreciative Inquiry

Article Classification: Case study/Original article

Introduction

The ageing of the global population coupled with advancements in medicine and technology, mean more people, of all ages, are living with increasingly complex care and support needs (Foresight, 2016, World Health Organisation, 2015). Current state provision of social care in the UK has failed to keep pace with current levels of demand, with an estimated 1.6 million people aged 65 plus in England to have unmet care needs (Reeves et al., 2023; Age UK, 2023). Although no comparable figures are published for Wales, the long-running cuts to local authority budgets suggests funding has failed to keep pace with demographic pressures and put pressure on the five million self-identified unpaid carers in England and Wales to provide support for their families and friends, and demand is unlikely to be met without significant funding increases (The King's Fund, 2023).

The consequence of this gap between care needs and care provision is likely to be experienced by families and friends who provide unpaid care. It is estimated there are around 5.7 million people in the UK providing unpaid care to ill and disabled family members, friends or neighbours (Carers UK, 2024) with an estimated economic contribution of up to £162 billion/year and around 9% of the population in England and Wales are providing 20 hours or more of care per week (Carers UK, 2024). In this paper, we use the terms 'carer', 'unpaid carer' and 'caregiver' interchangeably to refer to people providing unpaid care, although we recognise not every carer would identify themselves as such (Carers UK, 2016).

Recognition of the carer role and the contribution they make has increased since the 1960s (Yeandle, 2016). Unpaid carers often play a vital role in supporting others with illness or disability living in the community (Greenwood et al., 2019) and this was recognised in Wales with the publication of the Social Services and Wellbeing (Wales) Act 2014. In the UK, the National Institute for Health and Care Excellence (NICE) guidelines for supporting carers were published in 2020, highlighting this population as a policy priority. As the number of older people requiring care rises, it is important evidence is relevant to the contribution and support needs of people caring for older populations (Spiers et al., 2021).

Being a carer is recognised as a mixture of satisfactions and challenges (Brown and Brown, 2014). A recent review of literature reviews examined the consequences of caring and assessed carer interventions (Spiers et al., 2021). The results indicated the need to identify which groups of carers are most vulnerable to the impact of caring and under which conditions. When examining interventions the focus was on mental health and physical health was largely neglected (Spiers et al., 2021). The authors call for better evidence to understand the impact of unpaid caring on carers and to identify how carers can best be supported. This study addresses this call in part, by examining the experiences of unpaid carers when the person they care for have been hospitalised and what support can be offered to carers during this time. The study also included the experiences of hospital staff to gain a greater understanding of their roles when identifying and communicating with unpaid carers. Specifically, this research reports on what we believe to be one of the few unpaid carers' experience measures (UCEM) developed to assess carers' experiences of when a patient is being discharged from a hospital setting within one health board in Wales, UK.

A participatory action research approach was undertaken as part of a quality improvement project that focused on the frailty pathway and the development of the UCEM. The aim of the project was to improve the experience of unpaid carers through their involvement (especially the discharge planning process) throughout the frailty.

Background to the study

In the UK it is recognised avoidable lengthy hospital stays can negatively impact the frailer in our population, this is impacted by the lack of available beds or care in the community (Gridley et al., 2022). This highlights the importance of the carers role in supporting the discharge process (Carers Trust, 2023). In a damning report, Carers Wales (2022) found only 27% of unpaid carers stated they had been involved in the discharge process, with 48% stating they had not been involved and 65% stating they had not been consulted on their ability/willingness to provide care.

In 2021 there were approximately 310,000 unpaid carers in Wales (Office for National Statistics, 2021) They give care to family, friends or neighbours, in some cases in excess of 50 hours per week, worth over £8 billion to the Welsh economy. This is filling a shortfall that currently other services are unable to meet. However, despite their value, Carers Wales (2022) published a report in which 1,043 unpaid carers in Wales participated. 77% were worried about continuing to work while juggling caring responsibilities, 55% required paid leave to balance their work and caring roles and 33% needed to take unpaid leave to balance their responsibilities. Therefore, it was unsurprising to read 32% were struggling financially.

Health and Social Care Scotland (2019) identified the importance of the unpaid carer, recognising they are likely to have more knowledge about the persons practical needs post discharge and are likely to be pivotal in preventing readmission. This is reenforced by the Scotland Carers Act (2016), which states a hospital trust must ensure they include any carer of a person in their discharge. There is similar obligation within the legislation in Wales with the Social Services and Wellbeing (Wales) Act (2014) highlighting carers rights, with recent guidance from the Welsh Assembly Government (WAG) acknowledging all discharge plans should include the unpaid carer (WAG, 2023).

The Welsh Government set a national priority of identification of individuals with an unpaid carer role, valuing them and supporting them to make informed choices and assistance to access further support as required (Welsh Assembly Government (WAG), 2021). As a result of this, the identification of these individuals has become a standard part of the initial assessment when being admitted to Welsh hospitals.

A recent scoping review recognised good communication and involvement of the informal, or unpaid, carer is crucial to an effective discharge, particularly with older adults (Allen et al, 2023). Despite this, it is recognised worldwide unpaid carers are not routinely identified by other health professionals involved in the discharge process. An American study acknowledges their details, how they can provide support or the areas in which they need assistance in their role as the unpaid carer are often missed (Fong et al, 2023). Coleman and Roman (2015) suggests unpaid carers feel they lack information required to care for their loved ones once they return home.

Universally healthcare systems have developed mechanisms to measure patient experience with patient reported experience measures (PREM) being increasingly used to provide data from individual patients about their experiences of care (Gilmore et al., 2019; De Rosis et al. 2020; Male et al., 2017) at micro, meso and macro levels (Gilmore et al., 2023). What is less evident is how the experiences of unpaid carers are recorded, which is surprising given the pivotal role they hold within the healthcare system.

Methodology

Participatory action research (PAR) was employed for this study due to its practical and collaborative approach and the need to build relationships with the participants (staff and unpaid carers) (Kjellstrom and Mitchell, 2019). The distinctive features of PAR of generating knowledge or understanding to bring about change and its link to the quality improvement cycle (Best and Williams, 2024), were also congruent with this study.

Case study

This case study was undertaken by a multidisciplinary team within one health board in Wales, UK. The health board provides acute, primary, community, mental health and learning disabilities services via general and community hospitals, health centres and other sites located across three local authorities. This pilot study focuses on patients and unpaid carers associated with the frailty pathway and largely on discharge planning. The study was undertaken as part of the Health Board's 9-month quality improvement collaborative which ran from 2022 to 2023.

The quality improvement programme provided a structured education programme that covered a variety of improvement tools and techniques including the use of the model for improvement, process mapping, fishbone diagrams and PDSA cycles. Between the monthly education sessions, the team undertook an appreciative enquiry approach to action research in order to test the feasibility of their improvement learning and ideas. Action research is commonly used to improve healthcare practices (Lingard et al., 2008) and to enable staff to play a crucial role in bringing about change in their work (Parkin, 2009). Appreciative inquiry (AI) approach was favoured by the team as it looks for what is working well and how this can be developed and expanded, rather than a deficit approach (e.g. what is not working well and how do we improve this). AI is an action research method and was first used to enhance quality improvement in management (Cooperider et al., 2013) and more recently in the management of patient care (Luhalima et al., 2020). The AI five stage 5-D cycle enabled the team to highlight and build on good practice which helped with the engagement of staff, patients and carers. The five stages of the 5-D cycle were employed in three phases of the study (see table 1).

Insert table 1 about here

Data collection

A mixed methods approach to data collection was employed. Figure 1 shows the link between the action research AI approach used and the various stages of data collection, which include the following:

- Use of the model for improvement to define key research questions
- Scrutiny of related documents (e.g. carer documents and policies, etc.)
- Undertake analysis of strengths, weaknesses, opportunities and threats to the involvement of unpaid carers
- Identify key stakeholders that should be informed or involved in the project.
- Use of quality improvement tools (e.g. process map, fishbone diagram and driver diagram) to understand how unpaid carers were identified and involved in the discharge process.
- Audit of 88 patient records to establish when carers are identified within the patient frailty pathway
- Define Plan Do Study Act (PDSA) cycles to test and document small tests of change
- Online staff survey which consisted of 5 questions. This was distributed via a link/QR code to a Microsoft Form. Only nursing staff working within the frailty pathway were invited to participate.
- Unpaid carers Experience Measure (UCEM) which consisted of 17 questions (see supplementary file). Paper versions and links to an online Microsoft Form were provided to carers involved in the Frailty pathway.

Over the 12-month period of the project data were collected from one main site where the pilot study was conducted and another site to act as a comparator where appropriate and when data were available.

Insert figure 1 about here

Data analysis

Improvement tools were used to diagnose and define the area for improvement. Descriptive statistics were used to analyse the audit and survey data.

Ethics

As the study was categorised as an improvement project ethical approval was not required. The project was registered with the Health Board as part of the Quality Improvement Collaborative Programme. All participants were informed that participation was voluntary, and all data would be treated in confidence. All data were anonymised and only shared with the project team.

Results

This pilot study was guided by the Model for Improvement (Langley et al., 2009) which was employed to answer three key questions (see table 2).

Insert table 2 about here

Once the aim of the project had been established, improvement tools were used to gain a clear understanding of the frailty pathway. Baseline data were also collected as the data required for the project were not routinely collected. The results of the surveys and improvement activities are presented in this section.

Initial data collection

An analysis of the key stakeholders that were either important to or involved in the project. Key players included the unpaid carers, the project team, other healthcare workers involved in the frailty pathway. A SWOT analysis was constructed to identify what was working well and where opportunities for improvements existed.

A high-level process map (see figure 2) of the frailty pathway was constructed which visualised the patient's journey from admission to the frailty ward including discharge. It was evident from this visual that there was scope for unpaid carers to be included in the patient journey, but it was unclear how often carers were included and at what stage of the pathway. Using an appreciative enquiry approach, a fishbone diagram (also known as an Ishikawa diagram) was used to understand what was working well and where further improvements could be made (see figure 3). To gather baseline data to understand when unpaid carers were identified within the frailty pathway and audit of the Welsh Nursing Care Record (WNCR) was undertaken. A survey was designed to understand the staff experiences of identifying and supporting unpaid carers. The first PDSA (see Figure ?) was the distribution of this survey which consisted of 5 questions and was distributed by a link to a Microsoft Form and/or paper-based version to all nursing staff working within the frailty pathway. The second PDSA (see figure?) was the distribution of the revised UCEM survey to unpaid carers that had recent experience of the frailty pathway.

Insert figure??? about here
Insert figure 2 about here
Insert figure 3 about here

Collecting baseline data

Given the national picture it was expected that few unpaid carers were being proactively identified (Carers Wales, 2022). To obtain an understanding on where and when within the frailty pathway unpaid carers were being identified, it was necessary to conduct a local audit of the digital WNCR. It is locally recognised and agreed that WNCR should be completed with 48 hours of the patient being admitted to a ward or admission area. WNCR is not currently used in the Emergency Department (ED). The WNCRs for 88 patients who were admitted to the Frailty pathway (over 3 wards) and 1 medical ward were reviewed. This audit was performed manually working from a ward list and using the audit function on WNCR. From the records it was also possible to identify when the unpaid carer entry was made (i.e. on that ward or prior to arrival on that ward).

The audit results showed of the 88 patients records reviewed all except two had the unpaid carer field completed, with 28% (n=25) of patients having an unpaid carer. 50 of the 88 records were completed within the first 24 hours, 28 within 24-48 hours, and 8 within 4 days (see Figure 4). Those that took the longest were noted to have been admitted over a bank holiday period. In the remaining 2 records, the field was empty. On gathering these data, it was noted that most records were completed within a few hours of admission to the ward. Ideally, the record should be completed within 24 hours of admission.

Insert Figure 4 about here

Online Staff Survey PDSAs

After analysing the WNCR data, the project team wanted to see what staff interactions were taking place with the unpaid carers within the ward settings. A Microsoft Forms questionnaire was developed by the project team and distributed to nursing staff working within the frailty pathway. The purpose of the survey was to explore staff engagement with unpaid carers, by understand when conversations took place and the frequency of interactions.

In the first instance the survey was tested and reviewed by the project team (n=10) (PDSA 1). As a result of this small changes were made to wording of some of the questions. The revised version (PDSA 2) was then distributed to nurses, healthcare workers and other staff from the multidisciplinary team working within the Frailty pathway (e.g. admissions and three wards). 45 responses were received (see figure 5). There are 5 elements of missing data due to the questions within the survey not being made mandatory. 82.2% (n=37) of respondents were working along the Frailty pathway with 9% (n=4) working on an admissions unit and 4.4% (n=2) classed as "Other" these possibly reflecting MDT members attending the ward at that time. The remaining two respondents left this section blank.

Insert figure 5 about here

The respondents most frequently speaking with unpaid carers were ward-based staff (60%, n=27) including Health Care Assistants (HCA), registered nurses and ward sisters. Seven respondents classified their role as other which included Family Liaison officers, Physiotherapist and Advanced Nurse Practitioners. The remaining staff were made up of Doctors, Physiotherapists, Frailty Workers and Therapy Assistant Practitioners (see figure 6).

Insert Figure 6 about here

When asked about the frequency of communication with unpaid carers 60% (n=27) of respondents stated they spoke with carers on a daily basis, 40% (n=18) on a weekly basis. No respondents recorded never communicating with carers (see figure 7).

Insert figure 7 about here

Over 51% (n=23) of communications are made when the unpaid carer is visiting the admitted patient. Almost 11% (n=5) are during staff-initiated phone calls with the carer, and only 4% (n=2) when the carer initiates the call, the remaining responses 31% (n=14) were noted as a combination of these options (see figure 8).

Insert figure 8 about here

Respondents were asked what could be done to improve communication and information gathering. Common themes were unsurprisingly related to an appetite for further training around unpaid carer resources/leaflets and to have a general increase in knowledge. Several respondents also recorded having universal paperwork throughout specialisms would be helpful along with more resource and time to improve the frequency of communication and the ability to signpost to other services. Respondents also mentioned the need to incorporate carer information into the preexisting Comprehensive Geriatric Assessment (CGA) paperwork. Some respondents felt they already worked well with unpaid carers and others (20%, n=9) did not offer any improvements.

As these results were confined to one hospital site, to provide some comparative data the survey was distributed to staff involved in the Frailty pathway at a second general hospital within the Health Board. Prior to distribution the survey was revised to capture the job roles and ward names associated with hospital 2 (PDSA 3). The response rate was smaller than expected with 16 responses. Of those nearly 70% (n=11) were HCAs and Nursing staff. The remaining respondents being doctors, pharmacy staff and therapy staff.

Like hospital 1, most staff reported using visiting times to communicate with unpaid carers in Hospital 2 (87%, n=14). When asked about improvements in communication and information gathering suggestions included:

- Starting to collect unpaid carer details when patients are admitted via the emergency department;
- Exploring the opportunities to introduce weekly relatives' clinics or times on the wards when the unpaid carers can attend;
- Ensuring the availability of leaflets and posters for education purposes both for staff and unpaid carers.

PDSA 2 - Unpaid Carers' Experience Measure (UCEM)

An Unpaid Carers Experience Measure (UCEM) was devised by one member of the team prior to starting the improvement project. This paper-based version had undergone an initial pilot with eight responses received. This UCEM survey was revised and digitised using Microsoft Forms and then distributed to unpaid carers involved in the frailty pathway at both Hospital 1 and 2. Thirty-two responses were received over a 9-month period. The UCEM consists of 17 questions, including demographic questions such as gender and age. This information is shown below in table 3.

Insert table 3 about here

The majority of respondents (unpaid carers) were over the age of 50 (90.6%, n=29) with 14 (43.7%) carers being over the age of 70. They majority of respondents were female (78.1%, n=25) undertaking the unpaid carer role, which is perhaps unsurprising given that women are more likely to become carers and to provide more hours of unpaid care than men (Carers UK, 2024). Employment status was largely retired (59.4%, n=19), 8 (25%) worked full/part time. Most respondents identified as white British (87.6%, n=28), were married, and two (6.3%) people described themselves as having a disability. When asked about the age of those being cared for there was only two between the age of 18-29 with the majority of the "cared for" falling within the categories of 60-89 and one over the age of 90.

In relation to identifying when unpaid carers are identified within the frailty pathway. The results showed that of the 32 responses, 28 reported as an unpaid carer had been identified on or during the admission, 3 upon discharge and 1 not at all. The majority of these people (n=23), despite feeling recognised, did not always feel involved in discussions about the care needs of the patient although nine respondents said they were always included.

12 out of 32 (37.5%) unpaid carers said they were involved in the discharge planning process which was better than anticipated given the national picture. Eight (25%) of the respondents said they were not asked about what support they provide at home.

A variety of tasks are undertaken by the unpaid carer such as shopping, cooking, cleaning, emotional support, financial, transport, medical appointments and general administrative tasks. Out of 32 responses only 6 (18.75%) gave personal care. 69% (n=22) of carer respondents agreed they had been signposted to more information that could support them as the unpaid carer. A similar amount (n=21, 66%) felt this was helpful or very helpful.

Discussion

There is a growing recognition and appreciation of the important role that unpaid carers play within our healthcare system. Although national figures in Wales suggest that few unpaid carers are included in the care of patients when admitted to hospital, the audit data from this study show a more positive picture with the majority of carers being identified within 24 hours of the patient being admitted.

Previous research has indicated limited involvement of unpaid carers in older adult hospital-to-home transition interventions (Liebzeit et al., 2021) and the practice of engaging patients and their carers in day-to-day care was not systematically included in the routines of health services (Lilleheie et al., 2020). Our results show that most communication with carers tends to be with nursing staff and whilst carers are visiting the ward. A more recent review of the literature (Liebzeit et al., 2023) concluded there are few interventions that have targeted or included caregivers to improve discharge education and address support needs during the transition. Both staff and carer respondents indicated there was a need for further communication and signposting to support carers and effective discharge, particularly with older adults (Allen et al, 2023).

If carers are not able to frequently visit the ward, then communication may be limited to phone calls via the staff or the carer ringing the ward. It would seem progress has been made in identifying unpaid carers and the relevant information is recorded on the WNCR. However, more needs to be done to ensure that carers feel more involved, particularly in the discharge process. The early identification reported in this study will certainly help with this, but further work is needed to ensure more carers are involved throughout the care pathway and not confined to admission and point of discharge. The suggestion from ward staff of setting up weekly carer/relative clinics on the ward would aid the communication process and provide an opportunity to share information about support available to carers. Greater attention being paid towards unpaid carers is likely to have a positive impact on their personal need (knowledge for carrying out their caring duties) (Guilabert et al., 2018).

Our results show that the majority of carers had been signposted to more information that could support them, which again the majority found helpful. Recent research has examined caregivers’ perceived collaboration with hospital nurses and its impact on carers’ feelings of preparedness for caregiving (Hagedoorn et al., 2020). Our results indicate communication and relevant signposting is happening especially when visiting the wards. What is less clear is how these conversations are helping carers with preparing for discharge and ongoing caregiving. Further adaptation of the UCEM could assist in providing this information.

Conclusion

The aim of this action research mixed methods improvement project was to improve the experience of unpaid carers by identifying when and how there were involved in frailty care pathway. Contrary to national data, from collecting audit data, it was revealed that the majority of carers are identified within 24 hours of patients being admitted. However, the level of involvement was less and often relied on carers visiting the ward to ensure communication happens. To ensure carers are identified and involved in the frailty pathway, especially discharge planning, there is a need to ensure that processes and pathways are modified to enable staff the time and resources in which to communicate and collaborate with carers.

Another important element of this study was the piloting of a UCEM to understand the experiences of unpaid carers of the frailty pathway. The UCEM revealed a mixed picture in relation to their involvement and the offer of support and signposting to other services. As a result of this study additional training has been developed for ward staff in relation to the support services that are available within the locality to unpaid carers. In addition, the Discharge Support Service and Carers Officers (from the third sector) have been commissioned to provide additional support to carers and training to staff.

When mapping the frailty pathway, it was not obvious where and when unpaid carers should be identified and how involvement and communication is continued during the patient stay. It was not until the WNCR is completed, which is not available in ED, that staff have the opportunity to record the carer information. The UCEM needs to be fully embedded within the frailty pathway (from admission) to ensure the experiences of all unpaid carers are captured. Staff being aware and fully trained on the support services available are also important factors that will impact the carer experience.

The next stage of this improvement project is to continue to collate UCEM data and support healthcare practitioners to ensure the early and continuous involvement of unpaid carers within the frailty pathway. The project team also hope to implement the UCEM across other patient pathways.

Limitations of this Research

This quality improvement study is limited to one health organisation. Therefore, caution should be exercised when trying to generalise from the findings, especially due to the limited sample size of the survey data. An action research appreciative inquiry approach was taken which employed quality improvement tools and data sources. There are other improvement approaches that could have been used (e.g. Lean) which may have yielded different results. There is also an opportunity to include other study designs (e.g. observational, pre/post, experimental studies) as this improvement work expands to other sites and pathways.

Implications of the study and Further Research

This study will help managers and practitioners to better understand carer experience when the person they care for is admitted to hospital. To the best of our knowledge this is the first study that has trialled a UCEM within an acute frailty pathway setting. Further research is needed to extend this pilot to other patient pathways and to develop and evaluate interventions that will support practitioners in identifying and improving the experience of unpaid carers.

As with other experience measures (e.g. PREMs) the UCEM data need to be used at all levels within the organisation – micro, meso and macro level. This will ensure that the important role of unpaid carers continues to be recognised and valued within all healthcare systems. Further studies are needed to ensure these data are captured and any resulting interventions are tested and evaluated. Previous studies of carer experience have largely focused on the emotional burden of caring, further research is needed that examines experiences across care pathways and healthcare settings.

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