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## **Capturing the carer experience: a researcher's reflections**

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## **Abstract**

This paper reflects on the methodological challenges of conducting a study exploring the impact of being an informal carer for a person with palliative heart failure on carer quality of life and factors influential to carer's perception of caring

The study is a 2 phase sequential mixed methods study. A sample of carers was recruited from Heart Failure Nurses (HFN) caseloads in UK rural and urban settings. Carers were invited to complete the Family Quality of Life (FAMQOL) questionnaire, a tool developed for carers of heart failure patients. Participants were also asked to provide contact details if they are willing to be interviewed.

Each HFN was given 20 questionnaires. A third of carers who returned the completed questionnaires agreed to participate in an interview. Initial response rate was good but questionnaire returns gradually decreased over a few weeks. It transpired that due to the nature of the service delivery, on average each nurse distributed 5 questionnaires during a three month period.

The study highlights important methodological considerations for recruiting carers. As the intention was to begin the analysis of the questionnaires prior to commencing the second phase of the study the researcher was compelled to consider how

integration was maintained and how to improve access to carers for research.

Reflections and recommendations addressing these methodological challenges will be critically discussed in the paper.

### **Keywords**

Palliative heart failure

Mixed methods study

Informal carers

Gatekeepers

Hard to reach groups

## **Capturing the carer experience: a researcher's reflections**

The paper addresses important methodological issues to be considered when conducting mixed methods research with hard to reach, vulnerable populations. The paper will present the background to a research project conducted with informal carers of patients with palliative heart failure; the study design will be outlined and reflections on the procedural issues encountered during the research process will be considered in the context of the theoretical underpinning of mixed methods methodology.

### **Study background**

#### **The impact of caring for a person with Palliative Heart failure**

Heart failure presents a major challenge for health care delivery in an ageing population. It is a disease more common in older people; figures for the United Kingdom (UK) indicate the around 1% of men and women aged under 65 have heart failure; prevalence increases to 4% in men and women aged between 65 and 74, up to 25% in women and men aged 75 and above (British Heart Foundation, 2011). This presents not only the challenge of managing the condition but also the need to address the complexities associated with existing co morbidities and psychosocial issues in a vulnerable client group. A resulting factor of these complexities is that the condition is associated with frequent rehospitalisation and in the UK heart failure is the most common cause of medical admission to secondary care (Cowie, 2010).

As the numbers of adults living with long term conditions increases so does the number of family carers (Department of Health, 2010). Whilst caregivers of heart failure patients report similar issues to those caring for patients with other chronic

conditions, heart failure presents the additional challenge of coping with an unpredictable disease trajectory. Carers report that the physical requirements of the role impacts on their own health, with some carers being described as at the point of physical exhaustion (Pressler et al, 2009; Saunders, 2008; Pattenden et al, 2007). With a high prevalence of heart failure in people aged over 75, a consequence is that many of the carers are in the older age group themselves and therefore have their own health problems (Usher and Cammarata, 2009). Evidence suggests that carers may neglect their own health care needs as a result of a focus on meeting the needs of the patient (Usher and Cammarata, 2009). Predictors of carer burden include carer age, carers' health problems, lack of respite care and excessive hours of caring (Saunders, 2008).

### **Study Methodology**

Utilising a pragmatic philosophy a methodological approach, namely mixed methods (MM), was selected to measure the impact of being a carer for a patient with palliative heart failure on carer quality of life and explore factors relating to the carer's perception of caring. MM research requires a broad based and logical approach to an inquiry which guides selections of specific methods and is informed by a range rather than a singular conceptual position (Teddlie and Tashakkori, 2010). From the outset of the study, the research was a connected piece of work rather than two distinct studies and endeavoured to demonstrate that the quantitative and qualitative aspects of the study were interconnected. The intention of MM is that the approach maximises the strengths and weakness of both types of methodology. When selecting MM the researcher considered the appropriateness of the method/s selected to answer the research questions; would the use of MM deepen the understanding of the research population (Cameron 2011).

MM is commonly implemented in health care research as it draws on the strengths and perspectives of each method (Ostlund et al, 2011, Connelly, 2009). It creates opportunities for the researcher to recognise the influences of the physical world as well as the importance of reality and influence of human experience; in doing so it gives understanding of the complexities of the phenomenon being studied and the needs of diverse communities (Giddings, 2006 Ostlund et al, 2011).

Denscombe (2008) proposes that research paradigms mirror these communities and use methodologies that address a common purpose but may implement diverse methods to achieve this. Thus the research study recognised that the community being studied, namely carers and the impact of caring, consist of multiple dimensions which can overlap and causative effects which can be fluid from one dimension to another.

### **Study design**

To ensure transparency in the interconnected nature of the study, the researcher selected the most fitting MM study design. Three MM designs are proposed by Farquhar et al (2011) when specifically researching complex interventions in palliative care.

Sequential uses a design when one method occurs after the other in the same sample, a sub sample or a separate sample. The design also follows a sequential process of analysis in that one data set is analysed and the findings lead to the development of the next phase of the study. For example quantitative findings lead to theoretical sampling in an in-depth qualitative investigation or qualitative interviews influence the development of a quantitative survey.

A concurrent study design involves the triangulation of the different methods which are used concurrently. Creswell (2007) described a concurrent design as aiming to use different methods during a single data collection phase; in doing so the differing methods are intended to moderate the attributes, both strengths and weakness in each method (Gilbert 2006). The quantitative and qualitative elements of the study occur in parallel; data collection for both parts of the study occur at the same time; it is recognised that practicality may require that one part may start or finish later than the other but in essence the two parts of the study occur at the same time rather than the clear distinction of one part following the other (Teddlie and Tashakkori, 2009). The analysis and findings are integrated; this may be concurrent when each data set is interrogated at the same point to develop the whole picture of the phenomenon being studied (Onwuegbuzie and Teddlie 2003).

An integrated study design is when the qualitative and quantitative methods occur together and the tools are used with the same research subjects in the same interview.

### **Sequential design**

The present study selected a sequential design; the findings from the quantitative analysis confirming and influencing the focus of the semi structured interview schedule.

The study followed a deductive quantitative phase in which a cohort of informal carers of heart failure patients were asked to complete a validated Quality of Life (QoL) questionnaire, FAMQOL, designed specifically for this carer population (Nauser et al, 2011). The intention was for the responses of the questionnaire to be analysed and observations made regarding the range of scores indicating positive or

negative quality of life. The findings from the questionnaire would then be used to develop ideas for the semi structured interview schedule in the qualitative phase of the study. This was the inductive phase of research process in which carers were asked to participate in semi structured interviews and this was the dominant underpinning principle of the present study.

The overall aim in essence was to use a quantitative approach to observe QoL in informal carers of heart failure patients and examine correlations of background factors effecting QoL and a qualitative approach to explore positive and negative influences affecting QoL, and individual carer dimensions that impact on the caring experience.

### **Recruitment**

Community based heart failure nurse services (HFNS) have been established in recent years in the United Kingdom in response to increasing numbers of patients living with heart failure. The aim of the service is reduce unplanned emergency admissions and optimise patient quality of life (British Heart Foundation, 2008). The service offers a case management approach to nursing care; patients and carers are supported from point of referral to end of life. The HFNS in an urban population in the United Kingdom was viewed as the best route to access carers for several reasons.

The study sample would be homogenous in that carers were receiving the standard HFNS service; the patient population that the carers were supporting would be similar as they fitted the referral criteria of the HFNS. Additionally as the research population were a vulnerable group it was proposed that, as the carers had an existing rapport with the HFNS, the research would more likely be viewed as

trustworthy. The researcher had an existing professional relationship with the HFNS and this was used opportunistically to access a hard to reach study population.

A census sample of carers was recruited from the HFNS caseloads to complete the FAMQOL questionnaire (Nauser et al, 2011). The caregiver was defined as an unpaid person providing physical, practical and/or emotional care and support to a relative or friend in the patient's home. All carers of patients on the HFNS caseloads were contacted and asked to complete the questionnaire. Due to the carers being a vulnerable population the first contact with the carer was made by the nurse, with whom the carer had an established rapport. The researcher only made contact with the carer when they had agreed to participate in the research and had provided their contact details.

The questionnaire was self-administered (carers completed the questions themselves, in their own time). Participants were asked to return the questionnaire by a given date in a prepaid envelope to the researcher. Alongside the information sheet about the questionnaire carers were given information about the second phase of the study and asked to provide their contact details if they are willing to participate.

## **Results**

A total of 57 questionnaires were returned but the questionnaire returns were gradual, with an average of 5 questionnaires being received each month. A third of the participants who returned the questionnaire agreed to be contacted about participating in an interview.

Due to the gradual returns of the questionnaires the researcher was concerned that, if the first phase of the study extended over a lengthy period, there a risk that those participants who had agreed to be interviewed may no longer be interested or indeed, due to the nature of heart failure, no longer be caring for the person as the patient may have died. The researcher felt compelled to contact those carers who had expressed an interest in being interviewed to set up interview dates rather than run the risk of losing them due to a lengthy time lapse.

Reflecting on this methodological dilemma, in order not to compromise the sequential design of the present study, the research team agreed to set an end date for the quantitative phase whilst acknowledging that this incurred the risk of low responses for phase one. By identifying an end date, the researcher was able to begin the quantitative analysis prior to commencing phase two of the study in a timely manner in order not to lose carers who had expressed an interest in being interviewed.

Questionnaires returned after the end date were to be included in the descriptive statistics but not in the statistical analysis. Initial interviews were commenced prior to the end date but these interviews were viewed as pilots of the interview schedule. This proved to be a beneficial action as the pilot interviews affirmed the interview schedule.

## **Discussion**

A review of the literature relating to research priorities with family caregivers conducted by Hudson et al (2011) indicated that there remain significant gaps in research with carers. The review also highlighted particular challenges for researchers exploring issues relating to caregivers. These included problems associated with accessing carers to participate in studies and difficulties in determining who the main caregiver for the patient is. Consequently, as a research population, carers present a range of challenges that need to be addressed to facilitate their participation in research. Carduff et al (2014) proposes that carers may not identify themselves as carers, rather that they view the support they provide as being integral to their position as spouse, son/daughter. Additionally they may be reluctant to participate in research as they prioritise the needs of the person they are caring for and may feel guilty about talking about their needs and feelings.

In recognition of the issues associated with identifying and recruiting carers this study chose to access carers through community based Heart Failure Nurse Services (HFNS). Using clinical staff as gatekeepers can be both problematic and advantageous.

It could be proposed that the nurse may filter who they feel is appropriate for the study by their own interpretation of the inclusion criteria (Steinhauser et al, 2006). In the context of this study the nurse may be determining which patients are palliative and in doing so potentially exclude carers who would be fitting to be involved in the study. There is also an issue with gatekeepers subconsciously selecting those carers who they believe are most likely to complete the questionnaire and/or participate in an interview. Furthermore, with work load demands constantly increasing, the nurse

may not necessary prioritise the research study as their responsible for meeting the physical and psychosocial needs of their patients and carers.

As a single centre study the researcher was limited to the numbers of carers that could be accessed through the HFNS and it was acknowledged that this would impact on the number of questionnaire returns. Whilst questionnaires are commonly associated with low response rates (Bowling, 2014), the researcher further explored why the response rate of the questionnaires was gradual. It became evident that the low response rate was associated with the distribution of the questionnaires by the HFNS rather than non-return of the questionnaires.

By offering a case management model of nursing the nurse is a care coordinator; this involves continual communication with patients and their carers throughout the disease trajectory. A typical case load of each nurse was 40 patients, of which approximately half will have informal carer. New referrals to the service are triaged to a waiting list and therefore the nurse may be visiting the same patients and carers for a number of months. The nurses were distributing the questionnaires when they came into contact with the carers during home visits to the patient. It transpired that due to the nature of the service delivery, on average each nurse distributed 5 questionnaires during a three month period. Thus due to the manner in which they visited patients and carers there were clear implications for how this would impact on the length of the data collection in phase one of the study.

Conversely when considering informal carers as a hard to reach group the use of gatekeepers may be a positive recruitment strategy. The identification and subsequent recruitment into research of carers is a complicated process. Carers

commonly do not identify themselves as a carer but think of themselves as a relative or friend who is supporting a person with a debilitating condition (Barnes et al, 2005, Carduff et al, 2014).

A systematic review undertaken by Bonevski et al (2014) advocated specific strategies that can be incorporated into the study design to improve access to hard to reach populations. In relation to sampling, a convenience or census sample can be obtained through an organisation with high access to the target population. Bonevski et al (2014) acknowledge that this approach has limitations but argue that it presents pragmatic advantage for sampling a hard to reach group.

Miller et al (2003) advocates that positive interpersonal relationships between the research participants and the people recruiting into the study are essential in maximising participant recruitment. Participants' sense of respecting, liking and trust in the person recruiting has been demonstrated to improve accrual and retention throughout the research process (Miller et al, 2003).

Thus while there specific issues with questionnaire distribution the HFSN were an organisation that had access and an established rapport with the hard to reach study population.

### **Recommendations**

Whilst the HFNS was a successful manner of recruiting carers for the qualitative phase of the study, consideration should be given as to how future quantitative research using the FAMQOL tool maximises the response rate (Nauser et al, 2011). Potentially a more efficient way to complete the quantitative phase of the study over a shorter time scale, as well as being a direct approach to recruit to the qualitative

phase of the study, would be to use the FAMQOL as a telephone questionnaire. This is not to negate the positive use of the FAMQOL in the present study; the data analysis provided important background data around which the rich qualitative dialogue built a holistic picture of the carer experience.

The following actions were implemented by the research team to overcome the challenges posed in the study and to maintain the sequential design: a set end date was agreed for the quantitative phase of the study; ensuring the HFSN service were aware and updated regarding the study time line, questionnaire returns and recruitment of carers for the second phase of the study; writing to all carers who expressed an interest in being interviewed to provide a realistic estimate of when they could be expected to be contacted about being interviewed. The authors recommend that such practical considerations are integral in the development of MM with hard to reach/ complex study populations.

## **Conclusion**

It is proposed that research paradigms mirror the communities they are working with and use methodologies that address a common purpose to achieve this (Descombe, 2008). The complexities associated with the study population led to the researcher engaging a pragmatic research design to address the research questions. When reflecting on the research process and the challenges associated with recruiting to the quantitative phase of the study, the researcher used an iterative approach to meet the unfolding complexities. In this way the research experience, in common with caring for a person with heart failure, was unpredictable but rewarding a journey.

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