Refereed article

The information needs of informal carers: An analysis of the use of the Micro - Moment Time Line Interview

Frank Odhiambo, Janet Harrison and Mark Hepworth

Author

Dr Frank Odhiambo is an Assistant Programme Manager with the Water, Engineering and Development Centre (WEDC), Loughborough University where his role is to support existing contract work while developing new opportunities for work in information communication and dissemination. Prior to joining WEDC he worked as a Research Associated in the Department of Information Science, Loughborough University. Janet Harrison is a Lecturer in the Department of Information Science at Loughborough University. The focus of her research is information provision, access and use in the health/social care arena. Previous projects have included the Information Needs of Adolescents and those of People with Multiple Sclerosis. Dr Mark Hepworth is lecturer in the Department of Information Science at Loughborough University. He teaches Information Retrieval and also Developing User-Centred Information Services. The focus of his research is information behaviour and defining the information needs of specific communities. Recently funded projects have included the information needs of informal carers and also the information needs of people with Multiple Sclerosis.

Abstract

Informal carers and the contribution that they make in caring for people in the community is now recognised by government. The publication of the National Strategy for Carers attests to this. This paper presents the findings of a study into informal carers in Leicestershire, commissioned by Leicestershire Social Services Department. Specifically, the paper focuses on the use of the Sense-Making approach to study the informal carers' information needs. Sense-Making theory is explained and a discussion of the development and administration of the micro-timeline interview is given. Sample data derived form the interviews are reviewed followed by a discussion of the acceptability and appropriateness of the Sense-Making method in the context of understanding informal carers' information needs. The paper concludes that the Sense making methodology is an appropriate technique to use with this population .

Introduction

This study, commissioned by Leicestershire Social Services Department, was a study of informal carers in Leicestershire excluding Leicester City and Rutland. The objectives of the study were:

1. To provide an accurate picture of the demographic distribution of informal carers in the county of Leicestershire (excluding Leicester City and Rutland). This was to

include their age, gender, ethnicity, their relationship with the cared for person, the condition of the cared for person and the time spent caring.

2. To provide an understanding of the carers' information needs.

This paper focuses on the second objective of the study; namely, understanding the information needs of informal carers. Specifically, the paper focuses on the use of Dervin's Sense-Making approach [1] to study informal carers' information needs. Sense-Making was used to ensure that the study findings reflect the informal carers' experience from the perspective of the informal carer rather than from the service providers' point of view, thus providing a rich picture of the informal carers' situation. The paper reports on the methodological challenge of applying Sense-Making to a study of informal carers and discusses the development of the interview protocol, its acceptability to the carers and evaluates the appropriateness of Sense-Making in the context of informal carers.

The Impetus for the Research

In recent years, changing patterns of health and social care have placed greater emphasis on care in the community, which has become an important part of the health care system. As a result of this emphasis, the majority of care for people who are unable to care for themselves is through informal carers [2].

Since 1997, The UK government has made carers and issues surrounding care in the community a priority. It is suggested that one reason for this is that it is cheaper for the State if care is provided informally without pay. It is in the State's interest therefore to promote informal care and provide support so that relatives can continue to care. A second reason is the realisation by government of the enormous demands made of carers that have for too long gone unacknowledged [3]. Third, it has been recognised that being cared for in one's home is for many people, preferable to being in a care home or hospital, and that being at home enhances the cared for person's sense of well-being [4].

The government's focus on carers culminated in the publication of the National Strategy for Carers published in February 1999 [3]. The National Strategy identified for particular attention, carers of working age, carers of people with dementia and young carers, and was the driver for Leicestershire Social Services commissioning a survey of informal carers.

Informal Carers

It is estimated that there are six million informal carers in the UK of whom 855, 000 are providing care for more than 50 hours a week [5]. Generally speaking, both men and women care, although most family carers are women and men are far less likely to become carers. However, once they have become carers, men and women report similar experiences of caring. The majority of carers are spouses or partners followed by adults caring for elderly parents. Caring is found in all social classes, but like in many other spheres of life, those with more financial resources and greater advocacy skills, fare better [6]. About 75% of the total time devoted to caring comes from carers that live in the same household as the cared for person. It has also been found that because the physical demands of caring are often far greater than the physical demands made of

adults in their normal daily lives, carers are more likely than non-carers to have a longstanding physical disability or illness[(2] Moreover, most informal carers receive very little help from statutory agencies and they are often unaware of their entitlements.

Carers often have a wide range of information needs that require to be met and therefore, information is a vital part of support for informal carers [7]. The importance of timely, accurate and accessible information for carers is illustrated by the inclusion of an entire section on 'information for carers' in the National Strategy for Carers [3]. One area in which carers have a need for information is about the illness of the person cared for. Uncertainty about the course, treatment and prognosis of a disease is difficult for a carer to live with, especially when it is a close relation with the illness [7]. From the carer's perspective, diagnosis, prognosis and information about the disease helps in understanding the symptoms, thus allowing the carer to avoid blaming the cared for person, for something that he or she cannot control. For example, a carer would be less likely to interpret behavioural problems as misbehaviour when they have adequate information on the symptoms of Alzheimer's or dementia generally.

Most carers talk of the great satisfaction that they receive from looking after and nurturing a relative. For many, caring proves to be a very rewarding and positive experience. However, together with the feeling of satisfaction, there often are feelings of resentment and anger at the cared for person for changes in the carer's social life among other things. This is often accompanied by a sense of guilt on the part of the carer. In summary, though rewarding, caring can quickly become physically and economically costly. Thus the ability of informal carers to care for someone at home depends on the material, social and professional support available.

Informal carers in Leicestershire

The Leicestershire informal carers study involved a questionnaire survey of 2000 informal carers in Leicestershire followed by an interview study consisting of a subsample of 60 of the 2000 informal carers. The results of the questionnaire survey showed that 71% of the carers who responded [N=174], were aged between 40 and 69, and 68% were women a finding similar to other studies [5]. Despite many carers stating that their own health was good (73%), in a separate question carers reported suffering with back trouble (45%), depression (48%), exhaustion (54%), sleep problems (60%) and stress (76%). Seventy five per cent (75%) of the carers were unemployed and among those that were employed, the majority (63%), were employed part-time, a finding replicated in other studies [5]. Eighty eight per cent (88%) of the carers lived with the cared for person. The carers' relationship with the cared for person was as follows: 47% were either a spouse or partner, 29% looked after a child and 20% looked after elderly parents.

The cared for person was commonly above 75 years old and with a relatively even distribution between females and males (46% female, 54% male). Their medical condition was varied and often the cared for person had a number of medical complaints. However, by far the most predominant condition was stroke and confusion joint first, followed by Alzheimer's.

Methodology

Background to Sense-Making

Dervin's Sense-Making method has been built over a number of years since 1972 [8]. The aim of the method is to provide a way to understand information in specific contexts and also to understand how information needs come about and how they are resolved [1]. It has been described as a model by commentators but in Dervin's own writing, she says of Sense-Making that it is " a set of assumptions, a theoretic perspective, a methodological approach, a set of research methods and a practice" [9]. Dervin defines "Sense-Making" as a label for a coherent set of concepts and methods used to study how people construct sense of their worlds.

Philosophically, Sense-Making does not fall in either of the two main paradigmatic traditions: the positivist, neo-positivist tradition (giving rise to quantitative methods) or the constructivist, critical theory tradition (giving rise to qualitative methods). Rather, Sense-Making displays attributes of both traditions.

Sense-Making is predicated on a number of assumptions. The first and core assumption of Sense-Making is that reality is never unbroken but rather has gaps or discontinuities. It further assumes that because reality is constantly changing, the concept of gap is generalisable [1, 10].

The second assumption of Sense-Making is that information is not an objective entity existing independently of human beings. On the contrary, information is seen as a direct artefact of human observing which in turn is constrained by the following four factors:

- 1. Human Physiology: Human beings are unable to make some observations that other species can.
- 2. Present time-space. Because we are bound in time-space, our observing at any given time is limited by where we are.
- 3. Past time-space. We are descended from different histories and our histories in part, influence our observations today.
- 4. Future time-space. Our observations today rest partly upon our focus for the future. Further, following from the discontinuity assumption, our observing today cannot be valid for tomorrow.

These constraining factors on human observing imply that information is a subjective entity.

Dervin illustrates her method using what she calls the "Sense-Making metaphor" [10]. The metaphor has three elements to it: situation, gap and use. She argues that all information needs arise from a discontinuity or 'gap' in one's knowledge. Dervin's 'gap' is synonymous with what is usually referred to as information needs in other models. The *gap* develops out of a *situation* in time and space, which defines the context in which the information need arises. Finally, the *gap* is bridged by employing what she calls *uses* or *helps*.

It is important to recognise that the Sense-Making metaphor is operationalised using the Micro-Moment Time-Line Interview method. This method was chosen as the most suitable way to understand and gain information from the Informal Carer population and the scenarios they experience. The method entails asking the interviewee to talk through what happened in a given situation, step by step. For each of these steps, the interviewee describes what questions, or confusions he or she had and what needed to be made sense of. For the method to work well, the interviewer should ensure that at least two elements of the three-element situation-gap-use model are discussed and that data for each element is linked to a micro-moment.

Applying the Methodology

The interview protocol used for this study was developed with the aim of uncovering specific situations informal carers encounter and their associated information behaviours. Dervin's writings were used to inform the development of the protocol [1, 9]. The protocol was divided into three sections each focusing on the situations, gaps and uses elements of the model. In the first section, situations, interviewees were asked to think back over their time as a carer and name three events (bad or good), that stood out in their minds. This was intended to reveal the situations thereby defining the context of information need. After three events had been identified, for each event, the following questions were asked: The first question was to describe what had happened in these events, and what questions or confusions the interviewees had. These included what was not known and what difficulties or problems they had. The aim here was to clarify the 'situation'. These two questions formed the nucleus around which the rest of the interview was built.

The second section was a discussion of the nature of the 'gap'. What was it that was preventing the interviewees from moving forward? It also included questions about their knowledge of the 'gap'. Had they [interviewees], been in a similar 'gap' before? There was also a question on the importance to the interviewees of having the 'gap' bridged. This was followed with a question on how the 'gap' was bridged in the situation under discussion? Where did they go to find relevant answers, and how did they know where to go? What helped move them along?

There then followed a question about their success in moving through the 'gap'. Were they satisfied that they had resolved the discontinuity or 'gap'? Further, did they consider that they got a full answer? They were also asked what if anything acted as a barrier or constraint in finding an answer to close the 'gap'? That is, what hindered /stopped them, what was difficult, what obstacles did they face? This latter question was counterbalanced with a question about what they saw in particular as helping? This section on the nature of the 'gap' was closed with a general question about how they felt about the situation.

The last section of the interview protocol was on the uses made of the help /answers that had been obtained. The first question was whether the interviewees had an expectation that the answer would help once it was found. This was followed by a question to ascertain whether the answer helped in ways that were expected or in other ways. To

counterbalance this question, they were asked another question about whether they expected that the answer would present problems? And if so, were these expected to be new or old problems?

The next question asked how having the answer helped. Did it resolve the situation? This was again counterbalanced with a question did the answer hinder progress in any way or cause problems? These two questions were asked because Sense-Making focuses on how humans construct sense and therefore does not assume an automatic association between information [the answer] and use. The final question asked what, with hindsight, would have helped in finding the answer?

The initial interview protocol was piloted for unambiguity and comprehension using six informal carers who met the study criteria but were not used in the final analysis. As a result of the pilot, minor changes in the wording of some question were made. Following these changes, the content of the interview protocol was as described above.

Recruitment of Carer Interviewees

The first phase of the study consisted of a questionnaire survey. In order to recruit carers for the interview study, the 2000 informal carers in the questionnaire survey were asked to indicate when returning their questionnaires, their willingness or otherwise to participate in an interview study. Those who were interested were contacted by phone and a suitable time arranged for the interviews to take place. Interviews took place in the carers' homes [because they can seldom find time to be away from home due to the demands of the caring role] and were tape-recorded with the carers' permission. The researchers were mindful of the vulnerability of the interviewees and the potential sensitivity of the information to be captured. Therefore, at the outset of the interview, assurances were made as to confidentiality, and the interviewee's right to withdraw from the study at any time without giving a reason was emphasised. The average interview lasted about ninety minutes and a further thirty-minute post-interview winding down period was allowed for. All interviews were transcribed in full. The interviews were analysed using Atlas.ti which is a qualitative data analysis software.

Data derived using sense-making

Using Sense-Making it was possible to collect rich information which was carer-centred rather than system centred. An example of two interview transcriptions will be used to illustrate the type of data that it was possible to obtain using Sense-Making and thus to establish the carers' information needs and seeking, The first example used is that of an interview with a woman carer whose husband had recently been taken ill and was confined to a wheel-chair. This first example reflects the sort of situation that most people would expect carers to be in. The second example used is slightly different. It relates to a woman whose 14 year old daughter has epilepsy and exhibits challenging behaviour. She has always had behavioural problems but it is only with the onset of adolescence that her behavioural problem has become a cause for concern. Excerpts from the two interviews are given in sequence.

Interviewee I

Identifying Critical Situations

The aim of the first part of the interview protocol was to identify in what type of situations carers need information. When asked to think of any three events that stood out in her mind, this is what interviewee I said:

- A. The main thing is when I first started being a carer finding out all the information.
- Q. Yes
- A. Benefits and things like that

She could only identify the one situation described above. The interview proceeded with a discussion of this situation but later came back to identify two more situations which were also discussed. The focus here is on the 'situation' involving benefits.

Her husband had stopped work suddenly after a fall left him part-paralysed, and as a result, they were on a reduced income. The situation therefore was trying to sort out their financial matters.

Identifying the Nature of 'gap'

What was the 'gap'? What confusions, muddles did she have in her mind with regard to their situation? She said:

A - I didn't know what benefits Rob was on, what he was entitled to or anything or what I was entitled to.

Clearly, she was not sure at all about benefits entitlement. All that she knew was that her husband would be entitled to some benefit and perhaps she herself. Apart from this, she was uninformed. She knew that she had to do something about benefits but didn't really know what.

Thus far we have established what her situation was and what needs she had. What her 'gap' was. The interview then moved on to a discussion of the nature of her 'gap'.

She was asked how much did she know about benefits at the time:

Q - So how much did you know about benefits and the rest.

A - A little bit because I used to work in the Post Office but not a great deal.

Q - You used to work at the Post Office?

A - Yes

Q - So you had some idea of the sort of benefits you might be entitled to?

A - Yes, might be, but until you read up about them or ask about them you don't really know which ones apply and which don't, and if I

got something whether he would get less or anything like that, it was very complicated.

Though she had worked in a Post Office and thought she had some knowledge of benefits, it was only when she was in the situation of having to arrange benefits for herself that she realised how incomplete and inadequate her knowledge was for the task at hand. She also mentions how complicated the benefits system is – difficult to make sense of. However, one advantage she had was that she knew how and where to get the information she required as the following excerpt illustrates.

A - It was just a matter of looking it up and going to the local office and talking to people there, getting all the details.

Her choice of words suggests that it was an easy matter to find the answer she was looking for. She went on to say that having an answer was important to her because she needed to sort out their financial situation:

A - No I think I needed to know.

When asked if she thought she had got a complete answer concerning benefits she said:

A - I think so,

A tentative rather than emphatic answer. And what did she see as a barrier or hindrance when looking for an answer?

A - Only the complicated way things are done that's all, that was the biggest barrier, trying to find out all the details, it was all so complicated and confusing. The tax and benefits and things like that you know, it was just so confusing, you try to find some information for yourself and its just confusing, so you have got to go somewhere and talk to somebody about it or ring up and get an explanation.

She again mentions the word 'complicated' once and 'confusing' three times. It is clear at this point that what from the foregoing narrative at first seems a straightforward information seeking activity, is not. Rather, it was a confusing and complicated affair. She goes on to say that she would have liked to have been able to find out for herself all that she needed to know. In the event, she was forced into "talking to someone" about it; something she did not want to do.

So, in this situation, what was helpful in moving her along?

A - Yes the local benefits office, the person there was quite helpful and I also got hold of a copy of the Age Concern book, which gives details of all that about it, sort of thing. Mostly geared towards different kinds of benefits, there is quite a lot of useful information in there, well set out, easy to understand.

This answer shows that information seeking is not a linear activity in that she now mentions that she also had a copy of the Age Concern book which she relied upon but had not mentioned previously. She obviously found it useful because she says so and adds that it is well set out and easy to understand. When asked how she got hold of the Age Concern book she said:

A - Good question, I think his dad [Father in Law], mentioned that they did a book and he had seen it and it had got all the benefits in it.

Again this indicates that the information seeking process was not linear and pre-defined. She was talking to people about her situation in an effort to obtain an answer and was picking useful ideas along the way. She could not even remember straight away how she had come to hear about the Age Concern book. However, when she was asked how long it took to resolve the benefits situation this is what she said:

A - It took a little while to sort it out if I remember because I had to get all the details of that and then finding information and filling in the forms and everything, about an hour I should think.

When asked how she felt about the situation she said:

A - Slightly frustrated probably

Information Use

Turning to information uses she said that she expected the answer she got would resolve the problem and it helped in the way expected.

A - Yes, well we got the answers we needed in the end, all the information

She said that she did not expect that the information would present any problems and neither did it. She was then asked the following question:

Q - And so you did not encounter any problems as a result of what you are saying, like for instance, anything like, I thought I could do this or I could do that and then you subsequently learn that no I cant, that sort of thing

A - Oh, right. I think that would be part of working through the process of ending up with the final answer of what we were looking for.

This is a reference to the complicated and confusing nature of the benefits system.

How did having the answer help?

A - Well I suppose if we hadn't have got the answers we wouldn't have ended up with the correct benefits we were entitled to, we did need those answers and they helped us to get through to the right benefits.

How did the answer hinder? Having the answer did not hinder in any way.

Finally, when asked what with hindsight, would have helped, she said:

A - I think all the information was not easy to understand, everything is all so tied up with everything else and it affects everything else, one thing affects something else and that affects something else, you know you just don't know. You can't find information that easy you have got to go and dig it out from somewhere. I am not really used to read information and filling forms and that sort of thing, its all so complicated, if they could make that easier then I know they have got to have certain restraints to make sure everything is right, its just so complicated and all so tied up together, all the different benefits are all affecting each other and it doesn't make life easy at all. When you are looking for certain benefits, the Age Concern book is very good in some ways but it just shows you how there are all types of benefits, it refers to all the different things you can do this, you cant do that, if you get this somebody else might not get that, so complicated. If they could make - (sigh) - (laughter) - you'd expect them to make it complicated in the first place haven't they? A - I think they could simplify things definitely, I don't see why there are so many different allowances that do the same job, I mean it depends where you are living, what age you are, whether you are working whether you are not, whether you can work or whether you cant work, you know, this doesn't make sense.

She obviously had a hard time in finding an answer though she was able to make-sense of the *minefield* in the end.

Interviewee II

Identifying Critical Situations

Interviewee II had this to say about her situation: The focus here is her daughter's challenging behaviour and how to manage the situation.

A – Well it's very difficult because I have been saying for a very long time. I have been saying for 10 years that she has challenging behaviour, but it's also she is quite petite and like I have always been

able to control her. She doesn't listen to you, you can't... reason with her. She knows she is doing wrong one minute, but it doesn't stop her doing it the next minute.

When asked what questions, muddles and confusions she had, she said:

A - Her behaviour hasn't really changed, but she has just grown. So the behaviour becomes more of a problem, but she has actually picked up various unsociable language at the moment as well, and she has very good language, speaking language but she has little comprehension, of the spoken word and so sometimes she doesn't understand what she's saying, and that it is bad to say it. So she can say these things out in public and you get severe reactions from it. Things like that are quite difficult and I am actually finding that quite difficult to come to terms with.

Her daughter has always had challenging behaviour. The difference now is that her daughter has grown and is much more difficult to restrain physically and mentally. She has learnt unsociable language and uses it freely. As a result, this woman is constantly being embarrassed by her daughter's behaviour and consequently has a number of unanswered questions.

When asked what previous knowledge she had of managing and coping with challenging behaviour she said that she did not know anything at all and added:

A- No, no one actually tells you what to do about behaviour, they will say right we will just sit her down and occupy her and keep her calm and that or just hold her hand and things like that and hold her wrist's and that. The most they actually said was this is how you should deal with that, and we have been to behaviour psychologists and they haven't told us how to manage this at all.

Identifying the Nature of 'gap'

After identifying her 'situation' and discussing the questions she had, the interview turned to a discussion of the nature of her 'gap' and specifically, what information seeking strategies she used in order to find out what she required to know.

A – Well she went to a hospital in Oxford for her epilepsy which also had a behaviour management centre there as well and they just told me she should go to residential school for badly behaved children, which I think was totally inappropriate, because she would just copy the bad behaviour and wouldn't learn anything from it. That was four years ago we were told that. And I personally think that epilepsy and her behaviour go hand in hand, not in all cases but the children to have to deal with their own difficulties epilepsy and actually be able to run around and talk... I think behaviour goes hand in hand. It's very difficult to get a place and there are very few and a long distance away. Saying that, we are going to visit two... in the next three weeks. I just find it really difficult in that there are a lot of people out there who offer to help you I don't feel that you do get... you don't actually get told what to do about it.

She has been to doctors but in common with the findings of other interviews, there was a perception that no one was listening to her. Worse, the answer she was getting she considered 'inappropriate' and complains that no one could give her a straight answer. When asked whether in her opinion she obtained a full or partial answer she said that she only got partial information. This bearing in mind that she has been seeking an answer for ten years. She also said it was important that she find an answer.

A – Well I think it is important. I think she needs to behave socially, she needs to be socially acceptable, and at the moment the way we are going she in not going to be socially acceptable and I find that very difficult so I think it is really important that we have this information.

What did she see as an obstacle to her finding an answer:

A – Well there are very long waiting lists to get an appointment with a behaviour psychologist. I think when you are having a very bad time, it's something you need to see straight away, you know, they tend to have really bad behaviour and it can go on for weeks and weeks and you can't get to see anybody or discuss it with anybody. And then they go into decline and sort of be really good for a bit, and then you don't press for your appointment because you are like going through a good patch, then you hit another bad patch and still your appointment hasn't come through you know, and it's very difficult. And there are times when you really think I ought to get somebody on the phone to speak to at this particular moment in time, but you are really struggling and nothing can be done about it, you know.

How did she feel about this?

A – Not very satisfactory really. I think there should be some guidelines out there to tell you this is likely to happen, I think that's probably a let down really. But you don't know in most of these cases, and it may be because obviously progress in health... but there aren't many of these children who have grown into adulthood, and we don't know what happens because not all of the children are alike. They vary tremendously and if it wasn't for antibiotics she would have died when she was eight months old.

Information Use

Turning to information use, she said that having some information helped but that it did not help in the way expected.

A - Did it help in the way you expected or different ways?

A – Well I didn't expect to be experiencing now what I have, so I obviously didn't get that information, it's difficult to say really.

With respect to what would have helped with hindsight, she said:

A – Well I don't know, that's the other thing. I don't know what the answer is. I think personally she needs to go to an epilepsy school, where they can try and sort out her epilepsy as best they can. I think she needs 24 hour observation for a time and I think perhaps a couple of terms in a epileptic school with a medical facility on site, these schools do have hospitals on site and doctors and nurses and that. And I think that would be a good idea and then also look at her behaviour as well. I think that at this moment in time, that would be best thing. I think that all children with difficult epilepsy should have the opportunity to go to an epileptic school to try and get the epilepsy sorted.

When she was asked what her main information sources are she said:

A – Well when I want information I quite often go to the Family Support Centre and they have done a great deal for families to make you aware of, it links with the British Red Cross Family Support Centre and the manager there has... She is a mine of information and I mean at the moment Kate is going through this transitional process in the education when as soon as I mention transitional, with you all this information comes up and we get somebody who know about that and to talk to everybody on this and to be able to go to this place and to ask questions and if they don't know the answers they will try and find out for you. And they know all about the volunteers etc in the City and the County and they know all the places... And so mainly that's why I go, it's not until recently that I realised because Kate's so very very difficult, I had to go to the Social Worker and it's not until recently that I realised that they have access to everything.

Discussion

Acceptability of the Interview Protocol

Many carers undergo severe emotional stress in the course of their caring role. Mindful of this the researchers were apprehensive that the interview questions may prove to be too intrusive especially where emotional and sensitive situations were being discussed. In fact, this was not a problem. Quite the reverse, carers were keen to talk about their lives and experiences, almost finding a voice for their frustration. In only two interviews,

carers broke down emotionally but the remainder were able to cope very well considering that the method entails the interviewee reliving the situations . In this respect therefore, the interview protocol was acceptable to the informal carers and shows the wide applicability of the Sense-Making method in uncovering the lived experience of people in different contexts.

Appropriateness of the Sense-Making Method

The method was successful in teasing out situations that were important in the carers' daily lives. In the case of the first carer, state benefits was the first situation she thought of. This was true for many other carers too. Sense-Making is particularly effective because as with using the 'critical incident technique', the interviewee is not prompted in any way about the topic of the interview. Therefore any situations identified are those that are significant for the interviewee or the carer in this case. It was also possible to quickly establish what her need was and what type of information she required. Her mental state was also revealed in that she continually mentioned being confused and finding the whole process complicated.

For this particular carer, her knowledge of benefit entitlements, having worked in a Post Office, was insufficient to help her in finding an answer. This was because what she really needed to have was information on specific benefit entitlements and the interrelationships between different benefits, information which was not available in the booklets she had read and which she had not gleaned in her years paying out benefits. This is an important finding because it has a bearing on the development of relevant information solutions.

Also revealed is the curious way in which almost the natural instinct for people is to describe situations as a neat package. An example of this is when the present carer says of finding the information she needed:

A- "it was just a matter of looking it up and going to the local office and talking to people there, getting all the details."

However, it was not as simple or clear cut as this, as she clearly reveals further into the interview. The Sense-Making focus on barriers and hindrances, is therefore a valuable tool for teasing out the difficulties experienced by the interviewees which they edit out of their account of what happened and which represent their true experiences.

The question on how important it was to have the information is relevant because it is a measure of the amount of effort that will be expended in finding an answer. The present carer needed to have the information because it was directly related to her means of livelihood. It was therefore important that the 'gap' be bridged as she herself said:

A- "No, I think I needed to know."

This meant that she talked to people and was forced to "go and dig it out", something she might perhaps not have done had it not been as important to have an answer.

The Sense-Making method was also useful in revealing her information seeking strategies. First, she went to the benefits office; something most people would have done. However, she could not have found a full answer because she was also relying upon interpersonal contacts. We know this because she said her father-in-law mentioned the Age Concern book, said he had seen it and recommended it. So she went and obtained a copy of it. It can be argued that she used the path of least resistance for her information seeking because she chose methods that would involve speaking to people and not reading leaflets/booklets or using the Internet (they were connected to the Internet at home). The reason for this could be because (as she reveals at the end of the interview), she is not good at reading information and filling in forms. Admittedly she used the Age Concern book, (because it was recommended) but in her answer to what would have helped in hindsight, there is a sense that the book though useful, complicated the issue for her in a way. This might have had something to do with the fact that she had to read the book but perhaps also has and it did not relate to her situation but gave a generic overview of the benefit system. This has implications for the packaging and presentation of information in a way that relates to the need of the user. Information provision needs to relate to the situation of the user simplifying and synthesising the information variables.

By choosing this information seeking strategy, this carer did not use many information sources. Rather, she used one document and interpersonal contacts to obtain the answer that she wanted. Why did she use these sources? She confirmed that she does not like to have to read information of this kind and would much rather talk to someone one-to-one. It can be presumed she uses this method because it gives an opportunity for clarification to be made, muddles sorted out and importantly, the filtering of information so that relevant answers are found.

Eventually a satisfactory outcome was found as she was able to make sense of the benefits *minefield* through talking and some reading and was thus able to apply for and get the benefits that both her husband and herself were entitled to.

Conclusions

This article was about the use of the Sense-Making method in identifying the information needs of informal carers in a way that is anchored in their experience. A researcher can choose from a large number of research techniques, however, Sense-Making was well suited to the task and it was possible to uncover a variety of problematic 'situations' that the carers experienced. Even more valuable was that it was possible to identify types of 'situations' that carers experienced and have problems with. These situations were clustered under broad headings:

- severe emotional stress;
- lack of information;
- financial difficulty;
- contact with services (General Practice, nursing services, the benefits agency, social services and voluntary organisations).

Recommendations

These were organised to provide a lead for change for the service provider i.e. Social Services, Health and the Benefits Agency.

Key strands to the recommendations were :-

- The need for co-ordination between Social Service departments and other agencies;
- Improved access to information and the wider dissemination of information about support available;
- Improved information provision for service provider staff;
- Improved information provision for informal carers.

At a more detailed level, proposals for the content and delivery of specific information solutions that related to carers in general, specific types of carer and solutions that related to problematic situations experienced by informal carers were suggested. The need for a co-ordinated service for informal carers, that cut across service provider boundaries, was also highlighted. On the basis of this report and bearing in mind the recommendations Leicestershire Social Services were able to review their current initiatives and identify those that would help to address these recommendations. In addition new initiatives were instigated.

Summary

In summary, using the Sense-Making method, it was possible to identify informal carers' perceptions of critical situations associated with being an informal carer. It was also possible to isolate the factors that made the 'situations' problematic. As a result information solutions were proposed. On the basis of these findings and recommendations Leicestershire Social Services were able to evaluate their current service provision and make plans for further support of informal carers in Leicestershire. In this case, therefore, the sense-making approach and the micro-timeline technique proved useful for gathering relevant data and enriched the quantitative data derived from the questionnaire survey.

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WORD COUNT: 7,341