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CONFIDENTIALITY ISSUES IN INFORMATION SYSTEMS IN SOCIAL CARE

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ABSTRACT

This paper examines formal and informal information systems in homecare settings. Qualitative methods, including participant observation, were used, with 54 participants, and studying different types of social services provision. Results emphasise that homecare workers' priority is to their clients' care, and confidentiality may be seen as an obstruction to the sharing of information between care workers and other care professionals. Homecare workers perceive that information going back to care managers at the office needs to be filtered, and in some cases key workers take on that responsibility. The need to communicate risks often conflicts with homecare workers' concerns over confidentiality, and the establishment of trust when working in a client's home. New policies for electronic recording of care need to address these confidentiality concerns, as present guidelines appear inadequate.

INTRODUCTION

Much of the discussion about information sharing between health and social care has focused on the information within the health sector that might be required by social services staff and social care workers. The debate on confidentiality of electronic patient records has moved from the need to ensure that only those who need to see the record (or part of it) have access to it, to consideration of patient attitudes towards the consent process. A report by Cambridge Health Informatics (2002) for the electronic record demonstrator programme organised by the NHS Information Authority examines the ethical issues, the various technical options for electronic health records, recording of consent and support of confidentiality. Patient access to personal medical records is a major part of national policy – the argument being that more control should encourage the public to take responsibility for their health (and therefore be healthier).

Social care systems may have to fit into what is decided as the model for the electronic health record, although there are specific requirements for local government (Information Policy Unit, 2003). There is however, little recent research evidence, on the way detailed information requirements are negotiated within the social care sector, and how social care workers themselves view the confidentiality issues. Is patient access an issue within the social care sector? What would an effective electronic social care record look like, and how would it fit with current management of confidentiality? This paper discusses some of the findings from research on the information needs, and effectiveness of formal and information systems in the homecare sector.

BACKGROUND

More than ten years after The NHS and Community Care Act 1990, Calnan et al. (2003) found a total lack of respect for older people's dignity and privacy in physical, emotional and communication terms, although the thrust of the 1990 legislation was echoed in the National Service Framework for Older People (Department of Health, 2001). The Carers

National Association (CNA) suggested that patients did not mind carers being given information and carers should be kept in the picture with sufficient information to enable them to care safely (CNA, no date). However, Bungay and Alaszewski (2003) found that patients were not always in a position to give consent, because of their condition, being unconscious, or the focus on patient-centred care. In any fiduciary relationship, *'confidentiality is respect for people's secrets'* (Gillon, 1984). In medical contexts, *'The patient's right to confidentiality of his/her own individual health care information'* emerges from *'ethical principles'*, commonly the *'right to autonomy'* (Emson, 1994 p.165). Medical confidentiality is legally and professionally binding, and confidential information is defined as *'details about an individual patient'* (Woods et al. 2000 p.323). In statutory social care settings, confidentiality issues are enshrined in the conditions of employment and contract between client and care provider. In the study by Woods et al. (2000) of patients' views of palliative care services some health professionals were reticent to share information with patients and carers. When carers have almost sole responsibility for the care of the sick person, expectations within the triumvirate of patient, carer / family member and health professional change, carers arguably should have unequivocal rights to information about the person they are caring for. The political perception is that lay carers should receive information from the professional carers to help them in their caring role (Downie et al. 1995).

Prior to the establishment of Care Councils in England and Wales under the Care Standards Act 2000 the homecare sector was unregulated, and only members of the United Kingdom Home Care Association adhered to any kind of national code of conduct (UKHCA, 1996). Now there are enforceable codes of conduct, and service providers need to provide evidence of operational policies on confidentiality and other functions such as health and safety (Welsh Office, 1999). In 2000, Ministerial approval was granted to extend the Caldicott standards [applied in healthcare] to social care in England. The standards protect 'patient-identifiable-information' under the Data Protection Act [1998], the Human Rights Act [1998] and the common law duty of confidence (paras 4, 16 Section 1.0. Department of Health, 2001). The Caldicott Guardian's duty is to identify 'existing procedures for handling confidential personally-identifiable information', and 'identify existing flows of such information and the purposes for which it is used' (para 5 Section 1.0. *ibid.*).

METHODS

The ethnographic study used participant observation and in-depth interviewing techniques to collect data. Case studies of several homecare settings were conducted over an 18-month period between summer 2001 and autumn 2002 in a city in Wales. Within the settings, clients (n=7) receiving care were observed only, as no formal interviewing was conducted in the home. Informal conversations were possible with only four clients, but linguistic differences and clients' health conditions precluded verbal communication with the three remaining clients. Interviews with care workers and related care professionals were conducted throughout the fieldwork (Table 1). Care work conducted prior to the fieldwork acquainted the researcher with the role of formal care worker and allowed identification of potential participants. The latter were made aware of the

proposed research function at an early stage. One client and one care worker declined the offer to participate in the study.

The Local Research Ethics Committee (LREC) (together with the Department of Information Studies) approved the research procedures, and permission was granted by The Agency to which the researcher was attached. Written consent was requested and granted by participants, or advocates. Financial assistance for the study was provided by the Arts and Humanities Research Board, London.

Participant observation as a bona fide care worker was selected as a legitimate access route to otherwise closed homecare settings. Each client was physically, emotionally and socially vulnerable and incapacitated in some way. The method was viewed as less intrusive than other techniques, and a role in which the researcher could build a relationship of trust, with clients, care workers and other professionals over time. It was assumed that by gaining access to the homecare setting in this way, sustained observation of the delivery and receipt of care and the information flows and behaviours therein could be experienced in as natural a state as possible (Hammersley, 2002). Fieldnotes were always recorded off-site. Interviewees' comments could be verified and expanded from observation whilst working closely with them on regular and repeated occasions. Similar claims could be made of interviews with care managers, where comments could be reinforced through telephone conversations and actions of managers. Permission was sought to observe managers within their office environment, but this was declined. There were opportunities for spontaneous and informal contact with care workers outside the care setting. After completion of the fieldwork continued client care was guaranteed, as the researcher worked in team rather than solo care worker situations.

Professional / other role	Employer or agency affiliation (n)	Total
Care workers	The Agency (22), LA (4), Other private agencies (5)	31
Social workers includes PSSO / senior social workers	Local authority (PSSO = 1), (Senior social workers =2), (Social worker =1)	4
Community health professionals	Community dentist (1), Community nurse (1), Healthcare worker (1), Day services officer (1)	4
The Agency Management staff	The Agency care managers (2), trainer (1)	3
LA managers	Local authority	2
Voluntary agency director	Crossroads Wales	1
Family members	The Agency (1) and another private agency (1)	2
Clients (observed, <u>not</u> interviewed)	The Agency (6) and another private agency (1)	7
Total number of participants		54

Table 1: Role and affiliation of participants

In-depth interviews (n = 53) were conducted with consenting participants (Table 1), including two pilot interviews and eight follow-up interviews. Interviews were audio-

recorded and transcribed verbatim. Over 340 hours of observation data were conducted. A grounded approach to data coding and analysis was used, with theory emerging from the data. QSR NVIVO qualitative data analysis software was used for data analysis. Data were coded line by line, with several coding passes, and memos written to help in theory building. Samples of coded data were double-checked for coding reliability.

RESULTS

The research results are presented thematically, with extracts from the raw data chosen to illustrate the themes considered in the paper. The themes are selected to represent, as far as possible, the functions of the information systems (formal and informal) operating within this social care setting of homecare provision. The abbreviations are:

- CA_n = Care assistant affiliated to The Agency
- OPA_n = Care assistant affiliated to other private agency
- $LACA_n$ = Care assistant employed by the local authority
- CM_n = Care manager
- $DIR1$ = The Agency Director

Setting up the care package

It might be assumed that the negotiation of the care package would be a simple negotiation of needs between potential client, or their advocate, and the care manager. In reality, the assessment needs to be done on an ongoing basis as the process requires the establishment of trust between the care provider agency (whether private or public sector) and the client (or client's family).

'...because you have got two distinct roles I think, one is to establish what the client's needs are, and to build up a rapport, and then secondly to go through the business side of things.' (CM3)

While care managers at The Agency purposefully sought information on the client's welfare benefit situation, there were difficulties in obtaining sensitive information.

'...the home visit is a very false situation,...And we are only given the information the client wants us to have, we are a stranger going into their home and we are asking, for some quite personal information here.' (CM3)

'...and you think there's something not quite right here, you are not getting the full picture.' (CM2)

Issues such as alcoholism, homosexuality, terminal illness often took time to be revealed and only emerged when bonds of trust between care worker and client were secured.

Creating and developing the care package

Communicating with some of the frail and vulnerable clients was not easy when sensory impairment meant that body language, visual clues, and non-verbal communication were all necessary. The research found that approaches to care package development varied. At The Agency, one concern was to match the client to suitable care workers, and the manager aimed to collect information and evaluate a situation quickly. In the public sector social services, the care packages were instituted by social workers and assessed

later, but not always by managers. Care workers from another private agency claimed that assessments were not always done before the care package began.

'but our people should always come out before we, as a carer, go into the, situation, um they are supposed to risk assess it. And then get the finer details of what we need to know for this care plan, um that's not always done.' (OPA1)

A care manager confirmed that this was a problem, suggesting that as many as 70% of care plans change within the first week or so, because the care worker finds out when visiting the client that the care planned is not really what the person wants or needs.

Maintaining and monitoring care

Once a care package was initiated, and agreed, there would, in most cases, be ongoing dialogue between the relevant care manager and the care team. Some care managers were more pro-active than others – The Agency managers were respected for the follow-up given, but this was not universal among all social care providers.

'Because they don't...once you've had that client's name I've found that you don't really have much to do with the agency.' (OPA3)

The onus is on care workers to report back to managers, who are often presented with a very sanitised version of the care situation by the clients themselves.

'Now...when I go and visit on day two Mrs So-and-so is sitting there fully clothed – she hasn't been dressed for six months – fully clothed, make-up on, 'Tea, dear?' You know they try and present a different picture to us...so we depend very much on care assistants, for feedback.' (CM3)

Care workers reported how last minute hospital patient discharge or admissions of clients demanded rapid and fluid information flows between managers and care workers. In other cases the information went from care worker to manager, and the action taken has to be recorded and alerted to all the team.

'There is also a note from DAI's care manager who has paid a visit...in response to a letter concerning DAI's personal hygiene. Her note reinforces the need for extra care...due to his health problems. The note...requests everyone to sign the note to verify that they have read it.' (Obs Notes)

Building up the information system

Care worker / administrative assistant CA9, was one of three with a foot in both camps – clients' homes and the 'office', she explained the need to build up layers of information and the system dependent on such construction:

'Um, X's had a few problems um, recently, so they have all been reported back to the office because they need to go on file because also if a new care assistant goes into that client it's added information for her um and so they are kept up to speed because they won't have known what has gone on in the past. Because she's a long term client we have ... the information that we were given in the beginning and why we went in initially, since then there have been other, so that's additional information that would then go onto ...' (CA9).

Information flows were not always fluid and the information system might be better viewed as a jigsaw that **sometimes** fitted together well. The main jigsaw pieces were:

- communication with the client's family

- strategies for dealing with a change in a client's condition
- identifying potential problems
- risk assessment (health and safety) for the care worker
- risk assessment for the client
- out-of-hours support
- information exchanges between care workers concerning a particular client
- recording care provided formally
- information exchange between social care workers and health professionals

Some of the confidentiality issues are illustrated by the following extracts. Strategies for dealing with a change in a client's condition varied. In some cases a key worker for a particular client relayed information to the care manager. Key workers adopted several responsibilities. In one case the key worker had assumed responsibility for creating a client information archive, detailing personal and physical health care, preferences and functional capabilities, dietary and medication instructions, instructions for escorting the client to appointments and details of welfare benefit collection. Mostly, the key worker was the link between the care team and the office, and this arrangement helped streamline and filter the information sent to the agency.

'Or otherwise it could be all the team members constantly going to the agency'
(CA20)

'If you go to somebody for months and months and years and years, and situations change, but you're, changing with it...you get to the life of the family and I think in the end we probably know more than the agency' (CA30)

In other instances the care worker would judge that the information needed to be relayed urgently, and would go direct to the agency.

'...whether it be someone who had fallen down or um something completely changed they wouldn't eat or something like that, I would always ring The Agency' (CA22)

'well the mind's wandering...like one client nearly blew me up the other week!'
(CA19)

Client's conditions could fluctuate and in more well-established situations care workers adopted a wait-and-see approach, or dealt with the problem themselves without contacting The Agency. In some instances, the lack of communication, for whatever reason, caused problems when a change in routine had not been communicated, or certain professionals were hard to contact.

'...I think it's unfair for care assistants to go in blind but nobody had told us...but we can't be there 24/7. We can only give the information that we have got. ...If we wanted information on a particular client...to get hold of a social worker is almost impossible' (CM3)

Out of normal office hours, the on-call manager deals with problems that arise in covering client care, but has only limited access to client information.

'CA31 says that she does not know the care package in this situation and says that she is trying to persuade CA22 to cover the hours....I know that CA22 will not be able to cope with DJ1 on her own, I mention this to CA31 who knows she has to start again.' (Obs notes DJ1)

Trying to match client to care worker is a sensitive issue, and family members complain about care workers they consider inappropriate. In some care settings almost daily interactions between care workers and care managers were the norm, in other instances, contact was limited to crisis situations.

Information exchange between care workers was frequently informal, and done at shift changeover.

'She outlines what I have to do...and it involves a lot of personal care...she does however give the order in which she does his personal care, which is useful' (Obs Notes DA1)

Reassurance was often necessary when dealing with clients who had sensory problems, for example.

'I'm really worried about him...but I said he will be all right once he's rested his eye...and I didn't really feel that she needed to worry but she thought she ought to talk to me about it as the key one in there.' (CA20)

Sometimes the care workers met each other in the street or shopping and took advantage of the opportunity (given the limited time at shift changeover) to discuss any problems.

Although aware of the ethical problems associated with discussing clients in public areas, the neutral environment provided an opportunity that was missing otherwise.

'And you know you'd pass that information one, so we do need to communicate with one another, and it's not talking about them (the clients), it's talking for them really.' (CA30)

More formal recording of information takes place in a variety of ways. Log books, flow charts detailing the precise sequence of washing, notes attached to the fridge all served to underpin the recording of care delivered as well as 'aide memoires' for care staff on the next shift, or members of the family.

'It's all written up on the side of the fridge, so that anybody going in there can see it straight away, it says, morning, lunchtime, evening.' (CA13)

Occasionally the note on the fridge door helped to try to identify the scale of a possible problem, and care workers co-operated in the monitoring of such changes.

'CA1 has looked out the information leaflet from the drug package and highlighted the potential side effects. This sheet has been attached to the fridge door...' (Obs notes DA1)

Sometimes a diary was kept to track progress (or not) on a particular regime of treatment, and forms were required for clients with particular behavioural problems, to attempt to assess the particular trigger factors for types of behaviour. The formal record was not always a full reflection of the care provided.

'They are trying to keep a food diary, but I happen to know, uh, he does have little treats that don't get written down in the book.' (CA1)

Risk was a process of continuous negotiation, and care workers sometimes seemed reluctant to break confidentiality – at some risk to their own personal safety, or the expectations those in the care setting have of other staff.

'CM2...wishes that the girls would report it, she asks me why they don't and wonders if they fear reprisals from the family.' (Obs notes, meeting with CM2)

At other times key workers decided to withhold information from the client, and again the reasons were to protect the client. The care worker shows how she selected a trusted team member with whom she could discuss the issue:

'...and um when I discovered it, I knew that if I told him it would make his eye worse... And um I came to the conclusion that he didn't need to know because' 'So I initially decided I wouldn't tell him then. And I, then I talked to CA21 about it on the phone. And I said, are we going to tell him? Then he'll have to organise the insurance, and.... And so we discussed it and she um said, I don't think, it's going to make him ill, there's no point' (CA20).

Problems arose when care workers exceeded the designated duties but did not inform the care manager, and a new care worker was faced with different expectations of their assistance.

'...whether we ought to inform, uh our agency...That we are doing all these kinds of jobs, um and this is what the client expects of any new one that comes in.' (CA20)

Conversely, the care managers often presented the care situation as easier than it was.

'And some of them were truly horrendous, but according to her it was a lovely situation.' (CA9)

'So they let everybody sort of go in and feel their way around, because you know otherwise they wouldn't have any carers in there if we were told about you know...horrendous situations.' (CA29)

Managers impressed upon care workers the need to keep client information confidential, The Agency was affiliated to and bound by the code of ethics set by the United Kingdom Home Care Association. Care workers interpreted these strictures in light of the need to share information and talk for the client, as opposed to talking about them: *'And you know you'd pass that information on, so we do need to communicate with one another, and it's not talking about them it's talking...for them really to help out any situation'* (CA30). Her colleague reflected upon the tension between communication and confidentiality and the problems of isolation:

'...but um you sort of meet up with people, and say, oh you go into Mrs So-and-so? Uh yeah, so do I and, and then so long as DIR1 is not there. You, you uh sort of talk about that person, uh not, not because you want to gossip, but... It, it saves you from being isolated, I think at present with the information we get and the strict confidentiality that they, they insist on, it...it means that you, although you work with a client in a team you tend to work with a client in isolation' (CA23).

There was agreement that confidentiality confounded communication:

'But they always used to say, that you mustn't talk about your clients and I felt, rubbish you've got to talk about your clients. It's not talking about them outside, it's inside, in your own carers, to help you and to help the client. But they used to say, well, you mustn't mention names I think well, that is silly but it was needed, because how else are you going to learn about the person if there's a problem, if you don't talk to another assistant who's gone in, in the morning' (CA30).

DISCUSSION

Robinson (1991) argues that '*confidentiality is ultimately about the restriction of the flow of information*', and care workers were aware of the boundaries of access to information. Arksey et al. (1998) and Backlar (1996) showed that carers' need for information pre and post patient discharge was at odds with medical professionals' obligation to codes of conduct, and the difficulties care managers had in establishing a care package show how critical a period this may be. Establishing trust in the tense environment of an initial meeting is difficult, and the care manager therefore relies on care workers to fill in the gaps, over a period of time. Only care workers with office responsibilities showed any knowledge of how the information relayed to managers would be recorded or acted on, Care workers working as on-call deputy managers do not have access to the entire database, indicating that access controls need to allow for specific relationships and roles, as suggested in English policy proposals (Information Policy Unit, 2003, p.53).

An important task of the care worker is to foster a caring relationship and from this bonds of trust evolve. Care workers readily reported risk factors, such as change in a client's condition, potentially hazardous items in the home, or if the client was putting themselves at risk. Yet at times, care workers allowed the problem to reach crisis point before communication was attempted with the 'office', usually where there was volatility in the setting and / or care workers were uncertain the manager would respond. Reporting was determined by context: '*I suppose a lot depends on the situation really*' (CA9). In some care settings, information remains amongst 'hands-on' care workers, who make rational decisions about whether the information should leave the setting. Key workers take decisions themselves or with trusted colleagues. The closer the relationship between client and care workers the more likely it was that certain pieces of information would be withheld from care managers.

Much of the information exchange is informal and the more sensitive the information, the more likely it is that care workers will talk to each other, initially, rather than record formally, echoing research on nurses during handover (Kerr, 2002). Formal records may be used to sustain a case for changing the care package in some way when care workers believe that the current course of medication (for example) is not beneficial. Allowing formal patient access to the records is not something that most care workers would consider to be an issue. Their notes, or the logbook, are there for all to see, as these records are in most cases available for the family to view (and comment on, as well).

What is quite clear is that some of the important information may never be recorded formally, for reasons of confidentiality as understood by the care workers. Another problem is that care workers may not recognise the extent of the tacit knowledge they have. Will this matter if there is a move to electronic records in social care? It is very hard to answer this question, but several aspects of social care practice could be improved to make information exchange more useful to the staff and in many cases, lessen the possible damage to confidentiality. Handovers for 24/7 care need to allow time for care staff to update the incoming shift of any potential problems. For care that is delivered intermittently, the formal logbook needs to be supplemented with opportunities for care staff to discuss potential problems they have identified, in an environment that is secure,

and maintains confidentiality. For information sharing with health professionals, a care pathway approach (Cambridge Health Informatics, 2002, p.19) or confidentiality domains (Information Policy Unit, 2003, p.54) might work, if the pathway can differentiate responsibilities for dealing with the client, and sufficiently differentiate the 'trust footprint'.

CONCLUSIONS

The evidence from this research comes from one urban area, and is therefore limited to the observed practice of several social care agencies. Practice may be different in other parts of the country, where the balance of private/public sector provision affects the amount of care that is provided for individuals. The greater the time spent with the client, the closer the bonds between client and care worker are. We are left with a paradox – the closer the ties, the more likely it is that important, or 'privileged' information will be revealed. Conversely, the closer the ties, the less likely it is that anything but the required trace of this information will be recorded centrally with the agency. The role of key workers deserves further research as these staff effectively filter what can be transferred and what remains 'in the family'. The proposed Electronic Social Care Record has developed models for inter-agency consent and confidentiality and the concept of the service user team, with differing gradient of trust (Information Policy Unit, 2003, p.51) is one that might be applied to this situation. This research has indicated the importance of catering for these different degrees of trust and preferred levels of access to information.

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