Older Frequent Emergency Department Attenders’ Appraisal of Emergency Department Social Work

A Comparative UK and Swedish Study

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1. Introduction

Our study presents a comparative account of older frequent Emergency Department (ED)* attenders’ appraisal of ED based social work.

Anton, older frequent Emergency Department attender, to the Swedish interviewer: “You’ve been here to get my views, not just to hear a lot of compliments about it (ED Social work). I might just have said something that will make a difference... Anyway, that’s what I hope”.

Reflecting wider international trends (Gordon 2001), UK and Swedish health/social care policy has problematised older ED service users as “inappropriately” attending and being admitted through Emergency Departments, because of social care needs. As such they are viewed as major contributors to continuing increases in ED attendance and emergency hospital admissions (DH 2000; Thorslund et al 1997). Consequently ED based social workers are seen as having a key role in diverting older people from ED (re-)attendance or admission on social grounds, through meeting such needs (DH 2000). Amongst older ED attenders, frequent attenders have been identified as a prime group for diversion through ED social work intervention (Hansagi et al 2001; McLeod et al 2003).

Feedback from older frequent ED attenders themselves reveals that this approach is too simplistic. Our study indicates that these service users attend ED due to substantial health problems. It is because these also give rise to social care needs, that they require both medical/nursing and social work input. ED social work is of critical importance for older frequent ED attenders’ health in the short and longer term, but needs to be complemented by prompt and thorough ED medical and nursing care.

Policy and Practice Context

In the UK, ED social work has developed rapidly across the last few years, so that now 30% of EDs have a social worker as an integral Emergency Team member (Cooke et al 2000). In Sweden, ED based practice as a form of hospital social work is well established (Olsson and Hansagi 2001), and now nearly all EDs have ED based social workers. Since the Elderly Reform Act 1992 (National Board of Health and Welfare 1996a), their brief regarding older service users has been to concentrate on complex cases, while ED nursing staff deal with routine discharge arrangements, including those relating to social care.

To date, health and social care professionals have largely determined the criteria for evaluating ED social work. Very little attention has been paid to service users’ perspectives (Glasby and Littlechild 2000; Olsson and Hansagi 2001). As a result, the standpoint of a key party to ED social work - i.e. the service user who should benefit from it - has been omitted. Our study aims to address this shortcoming. We present an in-depth qualitative account of older frequent attenders’ appraisal of the significance of ED social work for promoting their well-being.
To simplify terminology and to reflect current trends, we have used the term Emergency Department throughout. While various terms are in use internationally viz. Accident and Emergency Department, Emergency Room, and Emergency Assessment Unit; the term Emergency Care is now widely employed in the UK, and Emergency Department in Sweden.
Research Objectives

Our account addresses the following questions:

- What did older frequent ED attenders identify as the main reasons for attending ED?
- What characterised the process of their engagement with ED social work?
- What aspects of ED social work did they value?
- What were the limitations and/or shortcomings of ED social work?
- What were their requirements for ED medical and nursing care?

Informed by service users’ perspective, and in the absence of any existing UK or Swedish evaluation of ED based social work with older frequent attenders, the Swedish and UK arms of our study are both of merit in their own right. However, its comparative perspective is critical. It explores the convergences and divergences between older ED frequent attenders’ experience in Sweden and the UK. This enables lessons from the more established and extensive Swedish ED social work presence to be drawn, while the current more concentrated UK focus on tackling ageism in and through hospital social work (DH 2001a) can inform our findings. UK older service users experience greater relative poverty than Swedish counterparts, and funding for welfare services is still relatively more generous in Sweden compared to the UK (National Board of Health and Social Welfare 2000). Nevertheless, in both countries hospital social work is being carried out in the context of long-term under-funding of social care services (McLeod and Sanden Eriksson 2002).

The Study

Characteristics of local settings:

UK Setting

In line with general UK practice, the ED was staffed by Emergency Care medical specialists. It included an observation ward. The department studied did not however receive trauma cases. The immediate working context of the ED social worker, reflected the continuing organisational drive to ensure that older patients do not enter or remain in the acute hospital system because social services fail to meet social care needs (Glasby 2003). The ED social worker remained under the management of the overall hospital social work team manager, and was funded by social services, as is usual in the UK. However, he was incorporated into a newly created multidisciplinary ED rapid response assessment team, set up with NHS funding, as a pilot initiative for twelve months. A senior nurse headed the team, which also comprised an occupational therapist (OT), as well as the social worker. Its brief was to provide a single multidisciplinary assessment in the ED, once the patient was medically stable, to all patients aged 65 or over. This was to ensure: that they were placed appropriately and received appropriate services; that unnecessary admission to an acute hospital bed was avoided; or if the patient was admitted to hospital, to promote speedy discharge because the assessment was already underway (Rapid Response Team Mission Statement 2002).
The ED rapid response team operated from 8.30am to 4.30pm weekdays and routinely received referrals from ED medical or nursing staff. Patient self-referrals virtually never occurred. Cases which then required longer-term social work were referred out to area teams or via hospital team managers to ward attached hospital social workers.

The following statistics convey the managerial imperatives underpinning this initiative. A survey the previous year had shown that 73.4% of all patients aged over 65 who had attended the ED were admitted to an acute hospital bed (Rapid Response Team Mission Statement 2002). Moreover the proportion of ED attendances by older service users was high, even bearing in mind that the ED in question only received adult patients. Across the five months - April to August 2003, when we recruited participants for our study, 41% of a total 12,086 ED attendances were by patients aged 65 or over (Hospital Statistics 2003).

The ED social worker dealt with nine cases a week, on average, of service users aged 65 and over, amounting to a total of 162 across the recruitment period for our study. Statistics for the proportion of his caseload who met our criteria for frequent attendance (3 attendances in 18 months) were not available for the whole period. However, they were available for the final month of the study and showed that they amounted to a total of 16 out of 40 cases i.e. 40%. This indicates that the service user group in question constitutes a very substantial proportion of the ED social worker caseload.

**Swedish Setting**

The Emergency Department was staffed by specialist medical practitioners working with teams of Emergency Care nurses, as is usual practice in Sweden (Olsson and Hansagi 2001). It included wards for observation and intermediate care. As in most Swedish settings, ED social work was funded and managed by the County Council as part of hospital services. The ED social worker was under the management of the Department of hospital social work, and had been an integral member of the ED staff since 1980. Referrals were ordinarily received from other EU medical or nursing staff. During office hours she provided a wide range of social work services, including bereavement counselling for patients and their families.

In her work, the ED social worker otherwise had no specific focus on providing services for patients aged 65 or over. The provision of home care for older patients followed the general care planning process instituted through the Elderly Reform Act (National Board of Health and Welfare 1996b). ED nursing staff routinely contacted area based social workers (employed by the local municipalities) to implement social care services. The ED social worker was only involved in especially complicated cases. Within the County where the ED was based, discussions - in which the hospital social work team had participated - had revealed deficiencies in social care provision for older people, particularly where they had multiple forms of impairment. The need for improvements in communication between relevant professionals concerning patients’ transition between hospital and home had also been identified (Personal communication from hospital manager 2003).

Across the recruitment period in Sweden - February to June 2003, 20.6% of 40,394 ED attendances were by patients aged 65 or over. Of all patients aged over 65 who attended ED, 45.9% were admitted to an acute hospital bed (Hospital Statistics 2003). The ED social worker
dealt with a total of 161 patients, 49% of whom (n=79) were aged 65 or over. A high proportion of her work with service users aged over 65, took the form of bereavement counselling with relatives of older attenders who had died in the ED. This represented 47% (n=37) of her caseload of older service users.

The percentage of the ED social worker’s caseload of older service users who comprised frequent attenders according to our criteria (3 attendances in 18 months), and relatives of frequent attenders who had died in ED, was 33% (n=14 frequent attenders, plus 12 relatives). This was somewhat lower than that of their UK counterpart, which is not surprising given that only the most complicated cases were referred to the ED social worker. Nevertheless it still comprised a substantial proportion of their caseload of older service users.

**Participants**

In both Sweden and the UK, the sample of service users had attended the ED at least three times across the past 18 months and were interviewed after their most recent attendance, during which they had all received a service from the ED social worker. To maintain confidentiality, pseudonyms are used throughout.

In the UK, ten service users in total were interviewed: five women and five men. They self-identified as White English or British, and in one case as Scots. Their ages ranged from 89-72, with a median age of 82. Most lived alone at home. With one exception, all the service users had relatively low incomes. As a means of representing older service users’ interests collectively in the research process, an independent Older People’s Health and Social Care Forum, reviewed a summary of key issues from the study, with feedback. Their commentary is incorporated in the Report.

In Sweden, seven service users were interviewed. Five were older frequent ED attenders. Two were bereaved spouses of older frequent ED attenders who had died in the ED. The bereaved spouses were included to reflect the fact that bereavement counselling is such a characteristic feature of ED social work practice.

Of the five older frequent ED users, two were women and three were men. Four self-identified as White Swedes and one as a White immigrant from another Nordic country. Their ages ranged from 85 to 68, with a median age of 75. All lived at home, two lived alone. One woman lived in extreme poverty, one man’s pension was below average. Two received the ordinary rate of pension, considered to provide an average standard of living and the remaining service user had an above average income.

The two bereaved spouses were both women aged 83 and 68, and White Swedish. One lived at home and one in very sheltered housing. The older woman received the ordinary rate of pension, the younger woman had an above average pension. They reported on both the care they had received as the next-of-kin and the care their husbands (aged 88 and 76 years respectively when they died) had received as older frequent ED attenders.
Summary of methodology

In both locations participants were recruited by the ED social worker, who obtained initial informed consent. In the UK, interviews were carried out by the UK researcher. In Sweden the interviews were carried out by a Masters level social worker, from another work setting.

In both localities interviews took place across a number of sites: at the participant’s home, in hospital, in residential care, or at a neutral site, chosen by the respondent. In Sweden two service users requested that another family member also participated in the interviews. With the agreement of service users the interviews were tape-recorded.

A detailed account of the methodology relating to both the Swedish and UK settings is provided in Appendix 2.

Structure of the Report

To put service users’ appraisal of ED social work in context, the Report begins by discussing how substantial ill-health is the key reason for their frequent ED attendance. It then explores the association between their ill-health and the need for ED social work, the process of contact, the positive outcomes of ED social work for their health in the short and longer term, together with its limitations. This is followed by an account of service users’ requirements of ED medical and nursing care, if it is to complement ED social work in addressing their health problems. Throughout, the Report identifies convergences and divergences between UK and Swedish experience, to provide an international perspective on the significance of ED social work for older frequent service users. The Older People’s Health and Social Care Forum who commented on the main UK findings rightly pointed out that the small scale of our research meant that it could not comprehensively represent the views of the substantial population of older people (Appendix 1:6). Nevertheless certain clear and important themes emerge from our exploratory study.
2. Ill-health: Key Reason for Emergency Department Attendance

Service users’ experience did not support the assumption that social care problems precipitate older patients’ frequent ED attendance. In both Sweden and the UK, service users’ accounts, together with social work assessments showed that with one exception, physical health problems constituted the reason for their most recent and previous ED attendances across the past 18 months. Moreover, the health problems concerned were substantial:

Agnes (Attended ED after a stroke): ‘The ambulance brought me to Casualty…I’d collapsed.’

Dennis (Arterial blockage that had led to a serious toe infection): ‘My foot turned septic, I went to the clinic to have a blood test and I went to another clinic to have it dressed …after dinner I had the shakes, everything went wrong, I didn’t know where I was. It came on all of a sudden. I got my son and daughter up here to see what was wrong with me. They had to get the ambulance…I finished up in hospital with an infection in me foot… when the (orthopaedic) consultant came to see me he said ‘We’ll have the toe off in the morning.’

Karl (History of fainting): ‘I was treated for the brain injury (cerebral haemorrhage) and then on the geriatric ward. Then I was discharged from there at the end of January. After a week at home I became very ill and fainted again. Back in the ambulance and in the ED again. Nobody knew what the problem was. They did all sorts of tests but couldn’t find out what had happened…. It’s a very funny feeling when you realise you are not invulnerable. It’s like balancing on the edge.’

Long-term problems

The most recent ED attendance related to the same known long-term health problem as most previous ED attendances.

Cicely (History of falls and transient ischaemic attacks (TIAs): ‘I’d had another fall at home. The doctor came and thought I ought to come to Casualty, after he had examined me.’

Elspeth (Had chronic obstructive pulmonary disease (COPD), commenting on the reasons for the most recent and previous ED visits): ‘It’s always the same thing, my breathing, when I can’t keep it under control.’

Anton (COPD and heart disease): ‘I’ve got these two fatal diseases, so of course I get worried. You lie down thinking, ‘How will the night end? Should I go to (the ED)... or wait?’ You don’t want to go unnecessarily, but they say it is better you come once too often, than too late, and maybe it is.’
Sudden manifestation

Despite the long-term nature of health problems associated with service users’ ED attendances, the manifestation of the specific health problem or deterioration in health, which led to the most recent ED attendance tended to be sudden.

Cyril (Sudden deterioration in his heart condition, profound hearing impairment): ‘I had no idea why I went (to the ED). You don’t know if you’re dead or alive, they bring you off anywhere. It’s a bit worrying. You’ve never met the people before.’

Ernest (History of falls, TIAs): ‘I just went down in a heap like…it gives you a shake…It (collapsing) goes back for some time.’

Carina (Wife of Erik who had had an aneurysm diagnosed three years previously and died suddenly while attending the ED): ‘It had been hurting, that’s why we had to go (to the ED). He was in pain and very worried. Even if you don’t talk about it every day, I was aware of what was going on and suffering as well.’

A ‘classic case’?

The rate of ED attendance across the sample of UK service users was fairly similar. Seven service users had each attended three times across 18 months; two, four times each; and one, five times. Among Swedish service users, two had each attended three times; four had attended somewhat more frequently: five, six, seven and ten times respectively. However, one service user, Dagny, had attended 38 times across 18 months.

Superficially, Dagny’s repeated attendance combined with the hardship she was experiencing, identified her situation as a ‘classic case’ of ‘excessive’ ED attendance driven by substantial social care needs. The authors have heard ED health care staff in both Sweden and the UK cite this phenomenon. Dagny lived a semi-homeless life. Although she had her own flat with her two sons, during the day she wandered the streets and local shopping centres, and would beg for money. When she came to the ED she was frequently hungry, unkempt and penniless. It also emerged that her sons were violent to her and took her money. To try to address Dagny’s state of destitution and the violence, on three occasions she had previously been referred to the ED social worker, but had refused to consider alternative residential care. Adult protection policies had also been considered, but she had not met the criteria.

Nevertheless, even in Dagny’s situation, on closer inspection, health problems played a major role in frequent attendance. She had been diagnosed with COPD and heart disease. Close scrutiny of the medical records for all her attendances revealed that with one exception, on each occasion medical staff had identified a physical health problem that required treatment. This predominantly took the form of acute shortness of breath or angina, but had also included a bleeding gastric ulcer, a bad fall, and twice, the physical effects of overdosing on sleeping pills. The exception had been when Dagny
had come to the ED in a very anxious state because one of her sons had been so violent to her that she had been frightened to stay at home. The need for ongoing medical care, albeit not provided by the ED, was recognised by ED medical staff themselves. Several entries in the medical records note ‘She has been told to go to her GP, but still comes to the ED.’

**Multiple Health Problems and Impairment**

All the service users had multiple health problems and not simply a single condition which had led to their most recent ED attendance.

Arthur (Attended ED because of deteriorating COPD): ‘I begin a course of chemo next Tuesday, and I don’t want to jeopardise that really. I was in here (the hospital) I had an operation six weeks ago for bowel cancer…That’s what the chemo’s about.’

Brenda (Attended ED following repeated falls) ‘I’ve got a lot of symptoms; kidney failure, heart failure, diabetes, skin very poor, cataracts.’

Bertil: (Attended ED due to pancreatitis; also had diabetes, heart disease and had had major surgery because of severe arthritis.) ‘I’ll tell you the full story. I don’t think anyone has survived everything I have, all the pain, all the surgery.’

Service users were also grappling with a range of forms of impairment: either physical or sensory, or in four cases what had been identified as mild short-term memory loss (See Table 1).

Geriatricians have argued that in the interests of older people’s longer-term health, such a complex health profile should act as a trigger for comprehensive medical assessment and review via presentation at acute medical care. It is recognised that improved care of chronic conditions can decrease the number of ED attendances and that global medical and social care review following repeated attendances can also reduce subsequent attendances (Cooke et al forthcoming). On these grounds they have warned of the dangers of strenuous efforts to ensure older people bypass contact with acute medical care facilities (Grimley Evans and Tallis 2001).
Table 1  Older Frequent ED Attenders: Identified Health Problems and Forms of Impairment

<table>
<thead>
<tr>
<th>Service User And Age</th>
<th>Identified Health Problems Recent ED Attendance</th>
<th>Other Problems</th>
<th>Forms of Impairment</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>UK:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sweden</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Anton (77)</td>
<td>Pneumonia</td>
<td>Heart disease. COPD.</td>
<td>Impaired mobility. Profoundly reduced energy. Impaired breathing</td>
</tr>
<tr>
<td>7. Fredrik (88) (Deceased, wife Beda interviewed)</td>
<td>Pneumonia</td>
<td>Diabetes. Periodic depression</td>
<td>Impaired mobility.</td>
</tr>
</tbody>
</table>
Active Workers for Their Own Health

Despite the substantial, multiple health problems and impairment they faced, in both Sweden and the UK all the service users (with the exception of Fredrik for whom we did not have clear evidence on this issue) came across as active workers for their own physical health. They displayed a stoical attitude to managing a daunting range of ill-health and impairments. On these grounds they could not be characterised as passively dependent on ED medical care, leading to its overuse. This finding echoes Tanner’s work which has shown that older service users with multiple health problems and impairments frequently stress the importance of maintaining independence by ‘keeping going’…reflected in numerous creative strategies …deployed to manage their difficulties in their own ways, relying on their own resources.’ (2001:261). Feedback from the Older People’s Health and Social Care Forum on the UK findings also reflected this concern to maintain independence, through their emphasis on the importance to older people of avoiding becoming ‘trapped’ in the health care system (Appendix 1:2)

Daphne (Attended ED with profound shortness of breath (SOB) and other symptoms of advanced heart disease): ‘I bought myself a chairlift, a chair that comes up, and a bath hoist when I had my knee replacement…. I’ve got crutches, a frame and a trolley… Up to a week ago ‘Ring and Ride’ (a door to door bus service) would fetch me. They lift you up on to the bus. I’d go to shopmobility and get a scooter, go round town and do the shopping. Commenting on treatment in the Rehabilitation Ward ‘I’m grateful for any help at the moment. I’m so anxious to get back home. I’d do anything to help myself.’

Elspeth (COPD): ‘At the time, [of her ED attendance] I was very very bad and I hadn’t had a decent wash in days – a strip down wash. I wouldn’t use the shower (in the bath) because the bath is so high…once I’ve put one leg over I have to stand and wait to get me breath back, to get the other one in, then I’ve got to wait again. Showering, I just stand there. If I can, I manage to soap meself and rinse. Before I can dry I’ve got to wait.’

Anton (Heart disease and COPD) had been housebound for more than a year): ‘I’m able to watch TV, maybe read a bit in the newspaper, but that’s about all I can manage. I get so tired when reading, but I really want to follow what’s going on…. I get tired from looking at the TV as well. I try not to worry, but carry on as normal…. (Commenting on moving between his bed and the toilet): To get there I use the wheel chair they got me to sit in for when I have a shower. You know, you need oxygen for everything.’ His wife interrupts: ‘My sister calls him ‘Superman’.’

Dagny (COPD and heart disease) did not comment on her reasons for her exceptionally frequent re-attendance at ED except to refer to her lung disease and chest pains. Nevertheless, even her pattern of attendance could be read as that of someone with scanty social and material resources being proactive in trying to maintain their health, by obtaining treatment from a trusted source of health care, while hanging on to independence from residential social care.
Conclusion

Feed-back from UK and Swedish older frequent ED service users, who had received ED social work, challenges their dismissal as inappropriate ED attenders. Substantial long-term ill-health manifested in periodic and sudden forms of deterioration was the key reason for ED attendance. Such attendance should trigger a comprehensive medical review, justified by this population’s complex health profile; instead of being used as a reason to distance them from contact with medical care via ED attendance. Service users also emerged as shouldering the demands of their ill-health alongside ED medical and nursing staff, as opposed to passively over-relying on their care.
3. Emergency Department Social Work: Critical Point of Access to Social Services

Service Users’ Social Care Requirements

Long-term substantial ill health, in combination with a wide range of impairments emerged as the primary reason for ED attendance. Not surprisingly therefore, prior to their most recent ED attendance, all the UK service users and all but one of the Swedish service users also already had considerable requirements for social care.

Brenda (Heart failure, kidney failure, diabetes, cataracts): ‘The home care workers have been coming for five years, one hour in the morning, an hour in the evening. It saves my husband, it’s what it’s for. They stop for two hours in the afternoon on Tuesday and Thursday while my husband goes shopping. I’m not to be left on my own. My husband is 84 and fit, he does the ironing and washing…he made the ramp for the back door.’

Cyril (Heart disease, arthritis, profound hearing impairment): ‘They (the home carers) come and wash you, get your meals. They come three times a day. I get up meself…They put the vacuum on twice a week. (Points to pendant alarm): Social Services got it for me…The woman over the road does the washing. She goes shopping. She pops in to see me, and her husband…. I don’t handle any money, she does it for me…I can call on this man next door, he’s even got a key…. This other man calls in, he does the lawn for me. It’s a big garden.’

Anna (Fracture, hearing impairment, mild cognitive impairment): ‘Before, I took care of myself. (After her fall resulting in a broken leg) I came to some kind of home, for rehabilitation. Call it whatever you like, I want to forget about it all…. You got a room and then there was a lavatory and then another similar room and in that room there was this old lady who sat there calling out for her husband, day-and-night. I wheeled myself over to her room to say hello. There she was, her head in her plate of pasta. You can imagine the conditions.’

Beda, had been the carer for her husband Fredrik who had had diabetes and periodic bouts of depression. They had lived in sheltered housing: ‘No! we never had anybody in to help, never. Not for a single hour.’ But then she had had a bad fall and the day after, her friend’s son found Fredrik sitting alone in the apartment, still in a state of shock. Beda was treated for her fracture and her husband was admitted to residential intermediate care before they returned home with extensive home care.

While grappling with such demanding situations, both Swedish and UK service users conveyed a stoical approach to their social life. Nevertheless, several accounts revealed a shocking degree of disablist/ageist social isolation:
Daphne (Had SOB, disease, arthritis, osteoporosis. Her only son lived half an hour’s drive away): ‘I don’t see much of him. He pops in briefly, very occasionally. Me and his wife, we don’t get on. Her family have absorbed him. I have grandchildren and a great grandchild. But my daughter-in-law never lets me see my grandchildren. That is a great sadness to me….Activities? ‘I read a lot, watch TV a little, do crosswords to keep my mind active. I don’t have any other relatives, no other friends – they’ve all died. Locally, the last of my friends died two years ago…. I don’t really go out socially.’

Ernest (Frequent falls, TIA’s impaired mobility): ‘I don’t have friends in the true sense of the word, who I see now…I don’t go out now…I occupy myself at home.’

Attitudes to social services’ care

In both Sweden and the UK, for somewhat different reasons, service users mostly needed to turn to care provided by social services rather than private care to supplement informal care. In the UK, with the exception of one service user whose husband had been an accountant, all the service users had a relatively low income in retirement, averaging £90-£120 p.w. and mostly composed of the state pension, together with welfare benefits. This level of income reflected the nature of the previous employment of most of the male service users or husbands of service users, which had been in skilled manual work. It precluded paying for substantial amounts of private care. In Sweden almost no private care is available to be purchased by service users (Thorslund et al 1997).

Consistent with their attitude to health care, both UK and Swedish service users displayed an independent approach to social services’ care. They wanted to do what they could for themselves. Where they felt they did need extra assistance to manage, they did not define themselves as having a right to social services, nor did they see it as their first port of call. They wanted to draw first on help from family and friends and saw social services as a residual service when they were in dire need. From several service users’ accounts, having to turn to social services was also seen as stigmatising.

Bertil: ‘I’ve got a pal who’s a cook. He makes me meals, puts them in containers for me and I pay him. It’s cheaper than if I have food boxes from social services. Social services…. have their own restaurant, but I don’t like it. I won’t go there, and try to eat their food.’

Arthur: ‘This lady comes down to me, she does all my cooking for me…a young girl does the shopping for me…Social services? I’ve never used them before, always been an independent old so and so.’

Elspeth: ‘I’ve got all me little jobs to do and it’s trying to fit them in and it’s so hard when my breathing’s bad. And I think, ‘Get up and go and do it’, but it is awful…No, I’ve had nothing to do with them (social services). Too independent I am.’

One service user’s situation also reflected the widespread situation where, notwithstanding their own multiple health problems and forms of impairment, service users can still be the main carers for
others (Dalley 1992). For the last four years, despite a good deal of input from his own children, Dennis (who had severe arthritis, and an arterial blockage) had remained the main carer for his wife who was housebound and could not be left alone. This was due to her experiencing a combination of cognitive impairment and a mental health disorder, together with impaired mobility. In Bernard’s case, although he could no longer sustain his own self-care at home, he was determined to keep up visiting his sister who was in residential care, as he was her only close relative: ‘She looked after me, that is why I am looking after her today. That’s a debt I have to repay.’

ED Social Work: Key Access Point to Social Services

Notwithstanding their reservations about turning to social services, feedback from service users on their most recent ED attendance, showed how in both the UK and Sweden the ED social worker acted as a key point of access to social services. There were three vital aspects to this. First, as other studies of hospital social work service users have found (McLeod and Sanden Eriksson 2002), a substantial number of service users in our sample (nearly half) were not currently receiving social services care, despite high levels of social care need. In such situations the ED social worker could arrange initial access to services. Bernard’s case illustrated the dangers for personal safety when the need for a substantial level of care had arisen, but there had previously been no input from social services and virtually no informal care. Bernard who lived alone had previously had a heart attack and attended the ED after he had subsequently collapsed. He also experienced sensory and cognitive impairment, but had received no social services care. A relative who was in intermittent contact had become concerned that his circumstances represented a serious level of neglect.

Extract from Rapid Response assessment: ‘Niece in contact: home a ‘death trap.’ Very cluttered, mouldy food in home. Patient very anxious about returning home, he feels he could collapse again and nobody would be around.’

Secondly, the ED social worker could facilitate the increase of existing social care input, in order to meet increased social care requirements due to deteriorating health. In Bertil’s case for example, he already had assistance with transport from social services, and meals on wheels. Now the severe pain and multiple serious health problems he was experiencing had reached a point where he needed help with cleaning and laundry, if he was to be able to maintain personal care.

Thirdly, the ED social worker could restart existing social services input promptly where service users’ health and well-being would have been imperilled without this happening. Cyril had advanced heart disease, physical impairment due to arthritis, continence requirements associated with powerful diuretics, and profound hearing impairment. Following Cyril’s attendance at the ED for treatment to stabilise swollen wrists and ankles, the ED social worker had liaised with the duty social worker in the area team responsible for the intensive package of home care Cyril received. This was to ensure services were restarted on the afternoon of the day Cyril was discharged. The ED social worker had also contacted the neighbour who was the key holder for Cyril, and provided vital informal care, to inform her of Cyril’s return. The researcher interviewed Cyril shortly before his home care worker arrived for the first call of the day. It was evident that in the absence of such input, there would have been a rapid deterioration in his hygiene and nutritional requirements being met, resulting in his health quickly being put at risk.
Contact with ED Social Work

Process

Despite service users’ need for social care via social services, overall there was little self-referral to ED social work. Although two Swedish service users referred themselves to the ED social workers, none of the UK service users did. None in the UK sample had known that there was a social worker based in ED, and by extension none of them therefore knew how to contact him. Arthur: ‘If he [ED social worker] hadn’t turned up on the bed like, it wouldn’t have crossed my mind.’ Cicely: ‘I never even thought of it [ED social work] before.’ In most cases in both Sweden and the UK, health care staff referred service users to the social worker, or in some cases the social worker had initiated contact.

Anna (had complained to health care staff about having to return to what she regarded as a sub-standard intermediate care nursing home): ‘First one doctor after another came, then one nurse after another and told me I had to go back there. Then the social worker came in the morning.’

Some service users would have been too ill at the outset, to make contact themselves. Agnes (Admitted through ED following a stroke): ‘I don’t remember seeing the [ED] social worker but I knew he came. The nurses said, ‘A man’s been to see you.’ Access to the ED social worker primarily via referral by health care staff might also be unproblematic, if one could guarantee health care staff could always identify and refer service users to the ED social worker when necessary. However, other studies indicate that this is not the case (McLeod 1997). In both Sweden and the UK only one service user in our sample had previously had contact with the ED social worker during several previous attendances.

These findings regarding access, in the context of a population with substantial social care needs suggest that for optimum take-up of the ED social work service, it is important to routinely inform older ED frequent attenders of the presence of the ED social worker and the services they offer, or to develop routine screening by/for ED social work. This proposal was corroborated by the Older People’s Health and Social Care Forum who commented ‘It is news that there are social workers in Accident and Emergency Departments. Most older people would not know that. It’s important that they do know.’ (Appendix 1:1)

Establishing Rapport

Once in contact with the ED social workers, service users emphasised how much they appreciated their personable and sensitive approach. This was clearly important in a situation where service users needed assistance with discussing and resolving some very worrying personal issues, while still possibly feeling very unwell and vulnerable. Most of the UK service users had also gone through the shock of ED attendance unaccompanied by family or friends. Cyril had attended ED with symptoms of advanced heart disease, had no close family, and profound hearing impairment: ‘He’s
(the ED social worker) a marvellous man...It’s like having a friend in hospital.’ Establishing such a rapport was also clearly important in assessing and planning the type of services that were required. Dennis, ‘Very helpful, very easy to talk to...He (the ED social worker) could advise. He said I was very easy to talk to too. I gave him the information he needed.

Ernest: ‘Very easy to talk to – no problems there. I felt I could open up.’

Anna: ‘She did what she had to do; her job. I remember how desperate I was...It felt good to talk to somebody who knew what should be done..... She made it very pleasant to have contact and it also had it’s funny moments.’

Conclusion

The substantial health problems which brought service users to the ED were associated with considerable social care needs. In keeping with their attitudes to managing their own health care, older frequent ED attenders displayed an independent approach to social care. They relied in the first place on their own efforts and informal care. Having to turn to social services for such care could also be regarded as stigmatising. Nevertheless, ED social work was a key access point for social services, of crucial significance for service users’ health and well-being. On these grounds, together with the low rate of self-referral, measures to promote service users’ access to ED social work merit consideration.
4. Significance of Emergency Department Social Work Intervention

Positive Evaluation

With two exceptions, service users in both Sweden and the UK uniformly assessed the ED social worker’s intervention as beneficial for their health and well-being (and in two cases that of their partner), both in the short and long term.

Liaison in service users’ interests

Reflecting professional: service user power divides, it can be difficult for service users to be kept informed and gain accurate information from pressured staff in health care settings about key decisions concerning their care (Glasby and Littlechild 2000). In a disablist way, these problems are amplified for service users in acute ill health and possibly with longstanding impairments. Caught in this situation, service users here, valued the ED social workers’ efforts on their behalf when they obtained accurate information for them and kept them informed of key decisions. There was clearly no alternative to ‘being on the spot’ to be able to do so.

Daphne was admitted to the Observation ward on ED with serious multiple health problems related to advanced heart disease, but remained determined if at all possible to return home, and had little support from her family. The ED social worker had double checked and briefed both health care staff and Daphne about complex arrangements for her transfer to a medical ward to try to stabilise her symptoms, prior to her being transferred to the rehabilitation unit. ‘He (the ED social worker) is a great ‘go-between.’ He makes sure they don’t just dump you into something. He introduces what’s going to happen to you. He has a very diplomatic manner.’

Cyril: ‘He (ED social worker) told me when I was going home.’

In Sweden one bereaved spouse also commended the ED social worker’s liaison role, as a positive feature of bereavement counselling, which features prominently in Swedish ED social work (Olsson 1997). Carina: (a bereaved spouse) ‘She (the ED social worker) asked things and stayed as long as we wanted. And when the doctor came she stayed and my daughter could ask things too. They (her daughters) are assistant nurses, so they had a lot of questions. We got all the answers we needed.... She also told us: ‘You can use the phone as much as you need’. ‘...cause I had to get in touch with the girls. When we had more questions she (ED social worker) got hold of the doctor again.’

The importance of an ED social worker having the necessary knowledge to carry out their key liaison role was also illustrated by the one complaint about ED social work input, from Anton who had found the newly qualified relief ED social worker’s performance lacking in this respect. ‘I remember it was difficult for us to get answers. We wanted to know about alternatives for
after-care. I don't know today how things will be in a fortnight’s time. Maybe I’ll need to go to some sort of residential care. Because at home, Birgitta (his wife) can’t manage forever... But she (ED social worker) didn’t know anything. Maybe she was a beginner, I don't know.’

Contact with the ED social worker could also bring peace of mind to service users while in hospital, through the ED social worker liasing over practical arrangements for their home setting, which in most cases they had had to leave precipitately and with no-one else there. Agnes (On the rehabilitation ward after attending ED following a stroke, described the relief the ED social worker’s practical measures had brought): ‘He [the ED social worker] made arrangements for home. He’s sorted things out there. There’s nothing more to be done.’

Averting imminent dangers

Evidence from service users on their requirements and the outcome of ED social work intervention, together with information from social work assessment documents indicated that in 50% cases there would have been a serious risk of imminent collapse of personal safety, imperilling health, without ED social work input.

At the point of his most recent ED attendance following a further collapse due to heart disease, Bernard who lived alone had been at risk of self-neglect, had had no social services assistance, no informal care and had been extremely anxious about yet another collapse associated with heart disease. He was also becoming aware of incipient short-term memory loss. The ED social worker had arranged a placement in Intermediate Residential Care, where Bernard was at present, prior to a fuller assessment. ‘I think it was a good idea...if I was at home on my own, I could collapse at home and no-one would know for days and days.... It’s very reassuring because I know I’m being looked after. I’m being looked after very well.’

Dennis had had to be admitted to hospital for an emergency amputation of his toe. He had been the main carer for his housebound wife with cognitive and mental health problems, who could not be left alone. ‘He (ED social worker) got in touch with everyone that I needed. The Home Care for the wife and things until I came out...I had no services before I went into hospital, me and my sons and daughters were doing the caring for the wife, I was doing the shopping and the cooking. My daughter comes up and does the washing and cleaning for us...The social worker sorted out someone to look after the wife during the afternoon/evening. It was just for a few hours, my son or daughter stopped here overnight. It’s only in desperation. It was really useful what he did for us. I found him very helpful...Also, an alarm put in. It’s for my benefit as well as the wife’s. It put my mind at rest. If I need another week in hospital, yes I’ll get in touch with him.’

After Anna had broken her leg she had no longer been able to manage at home. Following her admission through ED for the acute leg ulcer that had set in, the only alternative on offer in the locality for someone of her age, was to return to the intermediate care nursing home which she had been allocated, but which she disliked intensely. Anna was beside herself trying to decide what to do. Nevertheless, she described having confidence in the support the ED social worker offered her in taking this very hard decision. ‘She (the ED social worker) had her arms full of documents and
I thought: ‘there are so many lives contained in those sheets.’ Mine too… she (the ED social worker) sat down… talking it over with her was so important for me. I don’t remember many social workers, but I remember her.’

Bertil (Diabetes, chronic pancreatitis, heart disease, impaired mobility) ‘Yes, in fact I asked for a social worker. I told her about how difficult it was to decide to come to the ED. But I’m so frightened – what if I die here at home on the floor? Because I have fallen several times and woken up much later’ … and everything I needed (someone to listen and to arrange home care), she fulfilled – no doubt about that…the home care she put in still works.’

Cyril recognised the value of what ED social work had done in restarting his home care. Referring to the ED social worker, ‘They’re marvellous people…I’ve no complaints…They see you’re clean, get your food sorted out.’

Service users also identified the process of the ED social worker speeding up access to social services as most helpful. It was prompt and relieved them of the demands of negotiating social services’ bureaucracy, particularly when they had not previously had contact with social services.

Elspeth (With urgent community care requirements, but no previous social services’ home care): ‘He (ED social worker) helped me a lot. He did it all for me, got in contact with them and everything. He done it straightaway and he left me their phone number, but he was faxing it to them that I needed a visit.’

Bertil: ‘She (the ED social worker) was the one who made it happen (arrangements with social services). Got things going.’

**Longer-term well-being**

For some service users, ED social work input was important in underwriting well-being in the longer term, because of increased social care requirements associated either with sudden or gradual deterioration in health.

Arthur had attended ED with deteriorating COPD and was shortly due to start chemotherapy for bowel cancer. Prior to discharge, the ED social worker had briefed Arthur on applying for attendance allowance which he wanted to do himself, and supplied the necessary documentation. Arthur saw this as vital to reinforcing his arrangements for informal care at a point when he was going to be increasingly reliant on them. The ED social worker had also informed Arthur about how to contact social services if necessary, and how to obtain a response alarm. Arthur, on going ahead with applying for attendance allowance, ‘Can’t think of any way it (ED social work) could be improved. I’ve worked all my life and I wouldn’t know how to apply for anything really. I’m looking into that (attendance allowance) because there’s a young girl [who] does the shopping for me, and she’s on no benefits at all. The lady who does come down, she looks after her granddaughter…and I don’t think it’s quite fair she looks after the bab and me for nothing.’
Daphne had attended ED with shortness of breath and complications associated with advanced heart disease. Her mobility had also become increasingly impaired. Recently she had found greater difficulty in maintaining self-care, but had been reluctant to use social services care - which she had previously experienced as being of poor quality – to supplement the limited amount of private care she could afford. The ED social worker had arranged for an assessment for a care package to support her return home following completion of the rehabilitation programme in hospital. Daphne was determined if at all possible to return home despite formidable problems of ill health and impairment, and saw the ED social work input as key to this. ‘He (ED social worker) suggested more help: someone to help me get up in the morning; and going to bed. I have a job doing up bras, suspenders, putting on stockings…An intercom would help in answering the door…. He doesn’t push too far too quickly. You need that reassuring in hospital.’

Karl, following the onset of his fainting attacks, was not only very worried himself but had to cope with the fact that his wife was in a state. ‘Everything was very chaotic, you (his wife) were really shaken up by it all. Nobody asked us how we were coping, we had to take the initiative and get some help…It (contact with the ED social worker) had a very good effect on you too (looks at his wife), I thought. His wife Margareta continued: ‘Yes, it was a very good thing that she came. I could talk over how things were at home, how I kept thinking you (Karl) had died (when he had had his fainting attacks). I found it very comforting to talk to her about that… and she asked me if I wanted to continue to have contact with her.’ Karl, ‘She was very responsive to both our needs.’

Feed-back from Carina underlined how the ED social worker’s function as a bereavement counsellor, can not only hold benefits for the service user’s immediate well-being, but also in the longer term. ‘She (ED social worker) gave me some very useful information… and told me, what I needed to do during the very first days after my husband had died. Then she said, ‘You’re welcome to ring me, even if it’s not for some time.’ Because you miss so many questions when you are in such a state… Everything was very important to me then, even if it was a very minor thing.’

Support for Universal Provision

ED social work was already available across EDs in Sweden. Based on their positive appraisal, all the UK service users supported extending ED based social work, to become a universal provision in the UK. None identified further improvements that they would make to the service, except to extend the hours it was available, a point which the Older People’s Health Care Forum highlighted in their feedback (Appendix 1:3). The tone of their comments was epitomised by Bernard’s interjection: ‘They cover everything from A-Z and you can’t do more than that!’ Some service users reiterated the view that family members provided the first line of care, and the importance of the personal qualities of social workers in the traumatic context of ED attendance.

Bernard: ‘No older person can do without social workers, because a social worker will do for you what you can’t do for yourself…so you’ve got the minimum of worries, they take all your problems on their shoulders.’
Elspeth (Agreeing to all EDs having social workers): ‘A lot of people are like me, they are so independent, that they keep managing and managing and managing…And it’s hard work. Where if you had different things to help you, you would be so much better off.

Daphne: ‘It would be excellent if every ED could have a social worker – if you get that quality of person. I would imagine they’re few and far between.’

Cicely: ‘I think having a social worker in hospital is very useful. If you’re living with your family you might not need it. But if you haven’t, I think it’s always nice to have help… I could imagine it would be useful to have a social worker in Casualty in the evening.’

Limitations

Notwithstanding the substantial benefits of ED social work, service users’ accounts also revealed limitations to what it did provide, and limits to what it should be used to provide.

At risk - but not agreeing to services

Feed-back from two Swedish service users was a reminder that, even in cases where personal circumstances are worrying, ED social work for the most part can only function on the basis of consent from service users. Dagny attended ED very frequently with health problems, with the exception of one visit when she had been too scared to stay at home because of her son’s violence. However, when she came to ED she was always very hungry and generally unkempt. There had also been evidence that for some time she had been the victim of domestic violence from her son. Despite these conditions and a careful review, she still did not meet the criteria for Swedish adult protection procedures. When referred to the ED social worker on her most recent attendance, she commented that ‘The best thing is that you are able to sit down and talk’, but she had still refused to have any social care services. When she was interviewed for the research project she was very dejected, unwashed, her clothes were dirty and in rags. Nevertheless, she tried to keep up appearances, had still refused to accept social services and often spent her days begging for money since ‘we are three on my pension. It's me and my two sons’

Beda (Fredrik’s bereaved spouse) had never had any contact with her extended family after her mother, a single parent had died, when Beda was fifteen. She commented on how had all her life she had been ‘so very determined.’ Despite her recent fracture she had refused walking aids, as well as social service input: ‘Lisa (her one friend) thinks my home could do with a clean, but it doesn’t matter to me’. She also described how she had nothing to say to the ED social worker when she had seen her after her husband had suddenly died in the ED. ‘She asked about my life and I talked to her. But I didn’t really have anything to say, I did not want to talk, it was nothing... My life’s never amounted to a thing, never!’ But then Beda closed the interview by saying: ’But now, I don't know what to do.’

Organisational delays
A further limitation, which service users’ accounts both from Sweden and the UK revealed, did not concern ED social work input so much as organisational delays in longer term social work intervention. In Agnes’ and Brenda’s cases the ED social worker had promptly referred across to hospital and area social work teams respectively, for follow-up assessments. However, after two to three weeks the service users reported that they had not been visited by respectively the hospital and field social worker. In neither case was the service user’s personal safety in jeopardy. Agnes remained on the stroke rehabilitation unit. Brenda’s original package of home care had been reinstated and the field worker had telephoned her and her husband to check that she was OK, prior to reviewing the situation through a home visit in the following fortnight. Overall pressure of work on insufficient numbers of staff is the likely context for delays in face-to-face contact (Phillips and Waterson 2002). Nevertheless, the opportunity was lost both to maximise time for an assessment of social care needs in the course of rehabilitation; and for a timely reassessment when the service user had identified that they were struggling to meet increased social care needs following deterioration in health and mobility. As Brenda put it: ‘Now, just moving from chair to bed.’ She took the following measures to deal with personal hygiene: ‘I make do with a bowl. I sit in a bowl so I can wash myself ‘down below.’’ But her priority for personal hygiene was as follows: ‘I could do with one of those sit-in baths.’

Anna, after eventually receiving rehabilitative care in hospital, had returned home with home care six times a day initially. However, she gave several examples of breakdowns in arrangements between day and night staff, which had led to services not being provided in time. ‘Oh, this home care! These girls and they also employ young men as well; I think they do their best, they don’t mean to be unhelpful. But, the organisation, it’s a mess! One doesn’t know what the other is doing.’

**Limited quality of care**

Again, this limitation concerned the quality of longer-term social work provision rather than ED social work per se. Within current budgetary constraints, both in the UK and Swedish settings, the social services community care provision put in place through the ED social worker’s initial assessment and liaison provided for basic personal safety and maintenance of personal care. This was an important outcome. However, to a marked extent in the UK, follow-up interviews indicated that this level of provision did not necessarily enable service users with profound impairments, and very limited social and financial resources to obtain comprehensive social care or escape social isolation. To a lesser extent in the Swedish sample, there was also evidence of persistent social isolation.

Cyril was interviewed after his package of care had been reinstated following his ED attendance. Lacking a stairlift, he was confined to living downstairs, surrounded by continence aids, and with his bed in the front room. He did have frequent brief contact with neighbours and home carers from social services, but described the rest of his social life as follows: ‘No, I never go out. There was a man who used to take me down the town, but I can’t get about now. No [contact with nieces or nephews]. Sometimes I watch a football match on the tele. I’ve been a fan of X (local team) for years…. You’ve got to keep going. You’ve got the old stick. As long as you’ve got
the old television, you’re all right. You’ve got other people who are better off, to go anywhere for you. Interviewer, What do you most enjoy? ‘Watching football.’

Elspeth (With COPD, impaired mobility and profoundly impaired energy) was very pleased that the ED social worker’s intervention had led to improved social care, ‘Things are moving now!’ She had been assessed by an area social worker for a home care worker to come in Monday to Friday for half an hour each morning at 8am to help her with personal care, as she had been finding it increasingly difficult to wash and dress. In a week or two she was going to be assessed for aids and adaptations around the bungalow such as grab rails in the bathroom. It was still unclear whether she would get her heart’s desire: a walk-in shower. Although the daily visit from the home carer added a further brief element of social contact, there had been no finely tuned set of arrangements to boost her social life. Elspeth: ‘My friend comes once a week…My daughter comes every Saturday and they get all the shopping in. If I could get out occasionally, it’s a help. I talk to everybody that walks by if I’m in the garden. I haven’t a clue who they are but I’m talking to them, even if it’s only ‘Hello’….And I’ll look at babies, even though I’m not really interested in babies, I’ll say ‘Oh, what a lovely little kiddie’, just to have something to say. It’s hard when you’re on your own and stuck in. You’ve got nobody to discuss…you know, a different idea.’

Bertil (Was bereaved the previous year, suffers from chronic pain and has impaired mobility): ‘I don’t have a lot to do right now. This loneliness it’s a terrible thing. Just to sit here, listening to your own pain. You don’t have anybody to talk things over with. I’m not keen on visiting people either, because of the pain.’

Essential, not necessarily sufficient

In four cases, two from the UK and two from Sweden, service users’ experience also showed that in the interests of their health, it is important that ED social work assessment leading to social care or social care/nursing input, is not treated as a substitute for longer term specialist medical/nursing assessment and review, where needed. The UK service users concerned, welcomed input through ED social work as providing for their immediate personal safety. The evidence from their accounts confirmed this to be the case. Nevertheless, community and residential care did not obviate the need for thorough medical specialist assessment and review as well. The Older People’s Health and Social Care Forum took this issue very seriously (Appendix 1:5)

In Cicely’s case, her GP had referred her to the ED on a Friday, following a further fall and as experiencing profound weakness. Cicely had a history of falls, high blood pressure and TIAs, with four falls in the previous 10 days. She had felt very anxious about returning home where she lived alone, because she felt she could no longer manage. Arrangements were therefore made through the ED social worker for Cicely to be discharged direct to social services’ residential respite care after the weekend was over, and she was allowed to remain on the Observation Unit in ED until then. ‘The [ED] social worker arranged for someone to see me, to go for respite care. I live on my own you see. I feel more secure there [in respite care]. It’s a good idea: I don’t feel I’d cope very well at home on my own at the moment. I can hardly get my legs under me.’ Welcome
as such provision was, it did not render further specialist medical assessment of the underlying condition related to Cynthia’s debility and falls, irrelevant.

The tortuous sequence of events in Ernest’s case illustrates the same issue. He had attended ED following repeated falls at home, with a history of TIAs and having had a heart pacemaker fitted. He himself felt that the series of falls related to a long term problem which needed further exploration. ‘It goes back for some time…eventually Dr X, that’s the consultant saw me on January 3rd (seven months earlier) I couldn’t persuade him to even test me, ‘Oh that’s rheumatism,’ he said.’ Following ED attendance, Ernest was discharged home, where he lived alone, with a Hospital at Home (HAH) scheme arranged through the ED social worker, in place (providing three or four home care and community nursing visits a day for a week) and referred to social services to reassess his home care needs. Ernest agreed with the HAH scheme, and the Occupational Therapist’s and ED social work assessment that he might need more home care. He valued ED social work input ‘I feel that there’s somebody in the background there, to look after me if it came to an emergency.’ In the event, after a few days the home carers and community nurse became more concerned that Ernest was still having problems with coping between their visits. The community nurse therefore arranged that Ernest should re-attend the ED and be admitted to the Observation ward. Once admitted, a more extensive CT scan revealed ischaemic issues in his brain, which could account for his deteriorating condition, and he remained in hospital for further tests.

In the case of the two Swedish service users, both were happy with input from the ED social worker, but very unhappy that this was not complemented by thorough longer term medical treatment and care. Bertil suffered with severe chronic pain from pancreatitis, frequent vomiting, impaired mobility following hip and knee replacements and reduced energy associated with heart disease. He was very happy about the service he received from the ED social worker regarding home care. However, his frequent ED attendances at the hospital close to his home, had still not resulted in a viable programme of pain management through referral within the hospital. In a disabilist way, medical and nursing staff were still insisting that he attended a pain clinic at some distance, to obtain the necessary medication. Even with transport being provided in the form of a taxi service, Bertil could not manage to do this without great discomfort, given the forms of impairment he had. The vicious circle that resulted was re-attendance at the ED when his pain became overwhelming. ‘I was discharged, but I said to the doctor; ‘Why don’t you listen to me? Do you want me to die from it all?’ ..I feel so degraded …I feel like some sort of animal.’

In Anna’s case, following re-attendance at the ED for an ulcer on her fractured leg, she was very grateful for the support she had received from the ED social worker in making the difficult decision to return to the intermediate care nursing home. She acknowledged the need at that point for residential care of some sort. However, the nursing home failed to provide her with adequate medical follow-up and she had to be readmitted to the hospital orthopaedic ward for treatment.

**Conclusion**

Feedback from service users showed that ED social work has a vital role in contributing to older frequent ED attenders’ health, (and that of their partners). This is through meeting social care requirements associated with substantial ill-health and impairment. In some cases ED social work
averted imminent dangers to health by providing for immediate personal safety; in other cases it underwrote longer-term health and well-being. Despite these important benefits, there were some serious limitations to the outcomes of ED social work. For the most part these reflected current shortages in social care funding, especially in the UK. Service users’ experience also highlighted how even when they receive social care for the sake of their health, they should still receive the specialist follow-up medical/nursing assessment, review and treatment they need. Otherwise there is a danger of social care input becoming a diversionary substitute for medical care.

5. Emergency Department Medical and Nursing Care Requirements.

Older frequent ED attenders had clear requirements of the ED medical and nursing care they needed, together with ED social work, to address their health problems. In keeping with their basic stance of being active workers for their own health, they were keen to maintain as much independence as they could, while obtaining prompt and thorough ED medical/nursing care. These two key criteria for assessing such care, – that it should be prompt and thorough – were not at odds with, but congruent with officially identified goals for older people’s health care in both Sweden and the UK (DH 2000; National Board of Health and Welfare 2000). Service users’ definition of thoroughness not only included efforts to stabilise their condition in ED and care in ED that was responsive to their specific requirements. It also included ED attendance giving rise to arrangements for longer term treatment and follow-up: to optimise their chances of their condition remaining stable, to facilitate their management of it and to regain what degree of health was feasible. In these respects also, service users’ yardsticks were in line with official policy in both countries (DH 2001a; National Board of Health and Welfare 2000).

Prompt?

In both Sweden and the UK, the question of prompt treatment in ED has attracted a lot of attention in public debate and a raft of measures to improve ED care in this respect (DH 2001b; Andersson and Karlberg 2001). Prompt treatment was rightly very important to the service users, given the nature of the conditions that brought them to the ED. Its importance was reflected in both their positive and negative comments. Several Swedish service users criticised delays in ED care.

Anton (Attended ED with Pneumonia): ‘You know it’s awful, lying there for hours. Not knowing what’s going to happen. Those trolleys you know. They are not meant for lying on. It is like lying on a table with a hard case for a pillow.’

Beda’s husband Fredrik (Deceased, died from a cardiac arrest following pneumonia), had been discharged from intermediate care the day before a district nurse referred him to the ED. (Beda herself had been discharged from hospital two days earlier after fracturing her thigh bone). Beda commented: It was just like the last time, we were sitting there, waiting for ages. We came
home at eleven in the evening. Twice I went and asked for the doctor and was told, no, we couldn’t be seen yet. When we did eventually see the doctor, I told him that we had been planning to have an evening in watching the TV. And he said, ‘You might as well have done that.’ That's the way he put it. And then he said we could go home. …But we had to wait another two hours for transport. [Fredrik] could not lie down on that hard bench in the waiting room, so he got a chair with elbow rests, like this... We were very tired, no food or nothing and he’d had diabetes for 20 years.’

Only one UK service user identified a long wait in ED as a problem. (Although feedback from the Older People’s Health and Social Care Forum highlighted frequent incidents of this, to their knowledge – Appendix 1:4). Elspeth had had to wait several hours after arrival in ED. This had been very anxiety provoking, given that acute breathing difficulties were the reason for her attending. ‘I got there (GP Clinic at ED) at ten to twelve and I come out about quarter past four. I sat in the waiting room in the reception, the nurse had taken all my particulars from quarter past twelve, and I sat there and nothing had happened at three o’clock. Nobody had been to see I was all right.’

From her account, the situation had only finally been resolved on her own initiative ‘In the end I lost me temper because I needed a nebuliser. I was way overdue, so I went out to ‘em. And then things happened, the nurse came in with my paperwork and took me to the other [treatment room]. Interviewer: ‘Did they say why you’d been kept waiting so long?’ Elspeth: ‘No, they don’t tell you things like that. I couldn’t understand why a doctor hadn’t been into me because the nurse had said, ‘A doctor will come to see you now,’ when she took my particulars.’ (Elspeth was subsequently treated with steroids and antibiotics, and told that an incipient serious infection had probably exacerbated her breathing difficulties, and that this had been dealt with just in time to avoid the danger of it becoming full blown.)

Otherwise, service users did not highlight long waits in ED as a matter of concern. Indeed, in several cases they commended the promptness of the treatment they received:

Arthur (COPD): ‘When I came in, they put me on a nebuliser straightaway. They gave me a lung scan and antibiotics.’

Bernard (Describing previous attendance with his initial heart attack): ‘I was walking down the road one day, going visiting, when I collapsed. There was a lady and gentleman by the bus stop. The lady helped me up, the ambulance was called and I was taken to hospital. In hospital, I saw the nurses and the doctors, they were very helpful. They got me back on my feet. I can’t grumble.’

Anton (Attended with pneumonia, and had heart disease): ‘When it comes to anything to do with the heart, they’ve put money into that particular field, so they’re all very helpful.’

Carina (Husband Erik deceased, died from an aneurysm): ‘They always took care of us right away. You didn’t need to sit down in the waiting area and wait for hours, for example. When Erik arrived, they started taking blood tests right away.’
Thorough?

The second criterion service users employed to assess ED medical and nursing care was that it should be thorough. Several service users in both Sweden and the UK regarded the treatment they had had as meeting this requirement, with appropriate specialist medical/nursing follow-up either in hospital or the community. Evidence from their accounts supported this. At Arthur’s most recent ED attendance, in view of the deterioration in his breathing, after his condition was stabilised he was referred in hospital to the COPD nursing team and arrangements made for a programme of home visiting. This included briefing and support with self-management, such as anxiety reduction techniques to help facilitate breathing. Arthur was very anxious about having to cope with the deterioration in his breathing, and also the discovery of bowel cancer, but now happy with the care and ongoing support that had been arranged. ‘There’s going to be a few restrictions now…I had visions of being tied to a ventilator and nebuliser, I don’t know whether it’s a bit of anxiety about the operation I’ve just had or the treatment I’m going into (chemotherapy). You can’t help wondering whether this cancer is somewhere or another. The word terrifies me…The chest nurses will come to see me at home…I’m quite happy with the treatment I’ve had here.’

Once Elspeth had managed to obtain treatment in ED, she thought that it had been thorough, as had the follow-up care she had received (treatment at GP Clinic at ED, and follow up from Acute COPD Assessment (ACAS) Nurse, and her own GP): ‘He (ED based GP) put me on steroids again, eight a day. I was only just coming off them, and he put me on antibiotics and said that when I’d finished the steroids I should see my own GP - he was in (i.e. visited her at home) this morning…. I’d already got the ACAS nurse, she had been involved from when I’d been in [hospital] before…and she was in the room (in ED) …she’s come to see me again at home.’

Daphne (Attended ED because of shortness of breath and heart disease. She was referred to the Rehabilitation Ward following admission to a medical ward to stabilise her condition as far as possible), regarding rehabilitation: ‘They’ll try to get me to walk again. I’ve got arthritis, DVT, osteoporosis, leaky heart valves. They won’t operate, they can’t. They’re seeing how far they can get me going, so I can go home. If I can’t go home I can’t, but I’m going to make every effort.’

Karl (Attended ED after fainting, had previously had a cerebral haemorrhage): ‘Taking everything into consideration, they did a good job. They sent me to the CT scanner several times for an assessment. I’ve got confidence in them. If it’s the only place you’ve got to turn to, it’s good to feel confident in them.’

Service users nevertheless identified a series of shortcomings in the thoroughness of ED care and treatment as undermining their chances of regaining or maintaining their health: being discharged prematurely; their interests being marginalized in poorly resolved conflicts over appropriate treatment; being supplied with insufficient information; and instances of poor personal care.

Premature discharge
One service user, Arthur, was critical of previous ‘revolving door’ treatment in ED, which indicated to him that more time should have been taken to stabilise his condition more thoroughly. ‘Previous
attendance? For the same thing (COPD). I don’t know why I was in here one day and pushed out the next, only to get back two or three days later for the same thing. I wasn’t happy about that really.’

Anton (Pneumonia): ‘Quite often you’ve got to come back [to ED] because you were not well enough when they discharged you. Last time I was admitted due to pneumonia and they sent me home. Then I got ill again and had to go back. I had had the penicillin intravenously (in hospital), and it had an effect, but of course it was still in my body. The type of medication I had at home wasn’t the same as what I’d had intravenously. So really I needed to stay in hospital. It must be more expensive for the hospital to start all over again.’

**Poorly resolved conflicts**

Anton’s wife: ‘One doctor said, ‘You’ve got an infection.’ We had been waiting several hours by then…. The next doctor came and said, ‘No, that’s completely wrong, you haven’t got an infection. This is a case for the surgical specialty.’ But then we said, ‘You’ve got to do something.’ And he came with us to talk to the surgeon. But the surgeon said, ‘No absolutely not! I don’t want him here. It’s an infection. He’s not going on my ward.’

Karl on conflicting advice: ‘What was odd was that there (in the next department) they said they thought I should have had morphine. But here they said they had never let a patient leave in such pain. It was strange, because they were both specialist assessments…but you see a huge difference between a nurse who is really caring and one who is the opposite. There’s such a difference between different people doing the same job.’

**Insufficient information**

Anton: ‘When you are as old and sick as I am, you need more time…. The doctors are usually good. But when you have talked things over and you think of the question you would like to ask, he’s not there. They run away so damned fast when they’ve ‘done their work’, so to speak. They have too little time for the patients.’

**Poor personal care**

Daphne: ‘The majority of nurses are very good, and the doctors. But I’m afraid the night nurses ‘just don’t want to know.’ I said, ‘Don’t close the curtains.’ I couldn’t breathe, (admitted in the middle of a heat wave, with SOB) but they didn’t bother to listen. (She was also on powerful diuretics) they wouldn’t leave the commode.’

Beda referred to two occasions when she had been at the ED together with her husband – both lasted around 10 hours. The first time they were both provided with food, when staff realised how long they had been waiting and that her husband was a diabetic. However, on the last day of his life they waited in the ED for just as long, but had nothing to eat – a fact she can’t help thinking might have led to his death.

**Conclusion**
Older frequent ED attenders’ criteria for appraising ED medical and nursing care were consistent with working actively for their own health. They wanted such care to provide a prompt and thorough response, to offer the best chance of stabilising their health but also to help them maintain it or regain it in the short and longer term. Such criteria were also in line with official policy for optimal health care. Evidence from service users’ accounts indicated that to the extent that ED medical and nursing care met service users’ criteria, it made a positive contribution to service users’ health, alongside ED social work input.
6. Conclusions

Our comparative study suggests that frequent ED attenders constitute a significant proportion of older service users on ED social workers’ caseloads, both in Sweden and the UK. Moreover older frequent ED attenders should be recognised and responded to as co-workers for their health, alongside ED health and social care professionals. Their feedback on ED social work in both countries presents a series of important similarities and some differences in their experience, which merit further evaluation:

1. Feedback from older frequent ED attenders, who had received an ED social work service, indicates that substantial ill-health is the key reason for ED attendance.

2. Because substantial ill-health is associated with considerable social care requirements, ED social work constitutes a critical point of access to social services for older frequent ED attenders.

3. ED social work intervention is essential to maintaining the health of this service user group, both through averting imminent danger to personal safety and through underwriting physical well-being in the longer term. On this basis it should be available in all Emergency Departments in both countries.

4. The importance of ED social work for older frequent ED attenders’ health and well-being means access to this service should be maximised through:
   - Boosting self-referral by routine briefing on the availability and nature of services provided by the ED social worker, taking into account service users’ sensory and cognitive impairments.
   - Routine initial screening for ED social work.
   - Extending the service beyond office hours.
   - Addressing the under-representation of members of minority ethnic groups.
   - Emphasising that service users should have a right to social services, whose function is to assist independence. This is to counter the stigmatised image of social services among this service user group.

5. The role of ED social worker requires well-informed practitioners with excellent interpersonal and advocacy skills.

6. The need to boost social services’ resources in order to address organisational delays, provide more comprehensive input to redress ageist/disablist social isolation, and maintain personal care beyond the most basic level was evident to a marked degree in the experience of the UK sample, though to a lesser extent in the Swedish sample.

7. ED social work’s contribution to the health and well-being of older frequent ED attenders with multiple health problems and forms of impairment is indispensable. However, it should not be used as a substitute for longer-term specialist medical/nursing care on an in-patient or outpatient basis, when that is also needed.
8. ED social work needs to be complemented by prompt and thorough ED medical/nursing input for optimum care.

9. The substantial health care and social care needs of our sample suggest that frequent ED attendance by older service users should act as a trigger for a comprehensive medical/nursing and social work review of their requirements.

10. ED social worker’s role as bereavement counsellor is more extensive in Sweden. The possible benefits for the well-being of those close to deceased ED frequent attenders would repay further evaluation.

In short, our comparative study of older frequent ED attenders’ appraisal indicates that ED social work makes a crucial contribution to health and well-being. Optimising this requires improved access, highly skilled practitioners, increased funding for social services, and that ED social work is complemented by but does not act as a substitute for longer-term health care.
References


Appendix 1

Feedback from Older People’s Health and Social Care Forum on Main UK Findings

1. It is news that there are social workers in Accident and Emergency Departments (A&E). Most older people would not know that. It’s important that they do know.

2. The study would serve to highlight the need for a fresh look at the key role that A&E (Accident and Emergency Department) social workers can play in preventing older people who may need more social care than medical treatment, from entering the A&E system. Although it would cost more to increase the number of social workers being proactive within A&E, the benefits of such an exercise could result in a considerable saving in NHS costs. It could also help to avoid older people becoming “trapped in the system” through A&E.

3. It is incongruent to have a 24 hour A&E service and a 9-5 social care service, and so we concur with the study on this mismatch of services.

4. A likely reason why one of the service users in the study had to wait ‘several hours’ was because of the triage system being in operation and not known to the patient. Efficient communication is the key to the patient’s well-being. We know of many a patient being left without attention for periods of several hours.

5. Where older people discharged from hospital need medical/nursing care as a follow up as well as social care, they should not just be given social care as a substitute.

6. It is vital to get older patients’ evaluation of social work. But by the very nature of it, older people come from all walks of life and have attitudes from one extreme to another. Consequently the study with so few older people may not reflect the consensus of opinion of the 2.5 million older people of about 82 years of age.

7. Ageism as a form of discrimination is going to be outlawed by 2006 in the UK. But it is going to take some time before it is completely eradicated, because in our experience it is endemic in the NHS.
Appendix 2: Methodology

This comparative study was funded by a grant from the Nuffield Foundation in the UK and by the Stockholm County Council, Sweden. It was approved by the local Medical Research Ethics Committees in both countries. Strict confidentiality was maintained throughout. The methodology was as far as possible similar in both settings. However, there were certain variations which are reported below.

Sample

The UK
The ten service users who were interviewed met the following criteria. They had attended the ED at least three times during the past 18 months, had received a service from the ED social worker during their most recent attendance, were aged 65 or over, were well enough to be approached, not severely cognitively impaired, and gave informed consent.

Sweden
Seven ED social work service users were interviewed. They met the same criteria as the UK sample with one difference; two of the service users were not themselves frequent users of the ED but were older bereaved spouses of a deceased older frequent ED attender.

Recruitment

In both Sweden and the UK similar recruitment arrangements took place. At the end of health care and social work intervention in the ED, initial informed consent was obtained by the ED social worker for participation in the study, by approaching in turn, service users who met the criteria for inclusion. These were established by the social worker through working contact and working access to medical records.

Originally the criterion for frequent ED attendance was set at four attendances (including the most recent) across the past year. This was the definition commonly employed in other studies concerning adult frequent attenders (Olsson and Hansagi 2001). Service users with an age range of 75 or over were to be recruited. Delays to the start of recruitment across February were experienced in one setting due to unforeseen organisational difficulties. Subsequent difficulties in recruiting sufficient numbers to form a viable sample within the study’s five month time frame, led to joint recognition that the original criteria were too narrow: in respect of age and previous number of attendances across the past year. It became apparent that there were insufficient numbers of service users who met these criteria, who were well enough to be interviewed and/or sufficiently cognitively aware to give informed consent. With Ethics Committee approval, the criteria were reset as follows: an age range of 65 or over; with three ED attendances across the past 18 months, including the most recent attendance when service users received an ED social work service. Three ED attendances in
18 months still represented frequent attendance in the context of current UK and Swedish estimates. In the UK, available DH survey and Census data indicate that people aged 65 or over, attend ED on average once every four years (Personal communication DH statistics officer 2003). For the Swedish County where the hospital site for the fieldwork was located, available hospital survey and Census data indicate that people aged 65 or over, attend ED once every 2 years (Personal communication Hospital statistics officer 2003).

In the UK, fifteen older frequent attenders – nine women and six men - who met the criteria were originally approached to participate, one woman service user declined to give consent. Of the remaining 14 service users, four were prepared to participate, but did not proceed: three women service users, because of deteriorating health, one withdrawing initial consent. One male service user was subsequently found to have refused a service from the ED social worker. The final sample obtained was 10 rather than 12 as planned, and it did not prove possible to recruit 6 women: 4 men to reflect the gender balance among older ED attenders. Nor did it prove possible to recruit two members of minority ethnic groups to reflect the proportion of older members of minority groups in the locality. The ED social worker who recruited the sample commented that from his working experience, unfortunately this under-representation reflected the under-representation generally of members of minority ethnic groups accessing ED social work services.

In Sweden, two subgroups of ED social work users were addressed; older frequent ED attenders and older spouses, bereaved through the death of an older frequent ED attender.

Fourteen frequent ED service users aged 65 or over were referred to the social worker during the fieldwork period. One male service user could not subsequently be contacted. Two service users were not recruited due to dementia, and three because contact with the ED social worker proved to have been minimal or indirect. Two service users refused to give consent. Of the six who gave consent, one woman died before the interview could take place.

The bereaved relatives of twelve deceased frequent service users were referred to the ED social worker during the study period. Two older spouses in this group were randomly recruited.

The final sample obtained was seven and the gender balance did not reflect, as planned, that of older ED attenders. Nor did it prove possible to recruit two members of minority ethnic groups to reflect the proportion of older members of minority groups in the locality.

Interviewing and Analysis

In the UK, Victoria Staples worked as a researcher on the study during the early recruitment phase. Otherwise, all interviews were carried out by the first author. In Sweden all interviews were carried out by Natasja Andersson MA, a professionally qualified social worker, who was not connected to the hospital social work team.

In both the UK and Sweden, on the basis of reconfirmed consent, the participants were interviewed at home or where most convenient to them, on average two to three weeks after their most recent
ED attendance where they had received a service from the ED social worker. This was to enable
the significance of the ED service to be gauged, while memory of it and the most recent ED
attendance were still fresh. The bereaved spouses in the Swedish sample were interviewed 2
months after their bereavement, in connection with which they had received a service from the ED
social worker.

Large print versions of information and consent forms were used when required. With service
users’ agreement, the interviews were tape-recorded. In the UK, in the case of the profoundly deaf
service user, while conversation was possible, notes were taken and shown as the interview
progressed as it was not possible for him to check tape recorded comments. Interviews averaged
about an hour with breaks as appropriate to take account of service users’ health requirements.

Interviews were semi-structured, to provide service users with the opportunity to identify, raise and
elaborate on issues of greatest importance to them in relation to the main lines of inquiry. Together
with brief socio-biographical details, these comprised: an account of circumstances surrounding ED
attendances; experience and assessment of social work in ED (including its relationship to health
care); subsequent outcomes and current health and social care requirements. Consent was
reconfirmed at the end of each interview.

In the UK, analysis of all the interviews was carried out by the first author. After each interview,
tapes (or notes where taken) were reviewed, and all relevant and substantive points were noted and
illustrative quotations transcribed verbatim. In Sweden all interviews were transcribed verbatim by
the interviewer and together with a short report on circumstances when interviewing, handed over to
the second author, who carried out preliminary analysis. In both countries material was analysed
inductively to identify major themes, which were then further refined through being reviewed and
rechecked against the data.

As discussed in the Introduction, as a means of representing older service users’ interests
collectively in the research process, in the UK a draft summary of the findings (maintaining
confidentiality) were sent to an independent older service users’ health and social care forum for
review and feedback. Their comments were subsequently incorporated in Appendix 1 of the
Report. A completed summary of the findings was subsequently sent to each participant. To take
account of delays in recruitment, the original five month timescale for the project from February to
June 2003 was extended by three months to September 2003.

The two preliminary reports were shared between the authors and further analysed at a face to face
working meeting in August 2003, where similarities and differences in findings between the countries
were analysed for the present joint report.
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