ISSN 2044-4230

Medical Crises in Older People. Discussion paper series.

ISSN 2044-4230

Issue 13, March 2014

Today is Monday – the evidence base behind a film about the care of people with dementia and delirium in hospital

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Medical Crises in Older People: a NIHR research programme 2008-2013
And
Better Mental Health: a SDO research study 2008-2011

Undertaken by the University of Nottingham and the Nottingham University Hospital NHS Trust, UK

Workstream 1: towards improving the care of people with mental health problems in general hospitals. Development and evaluation of a medical and mental health unit.

Workstream 2: Development and evaluation of interface geriatrics for older people attending an AMU

Workstream 3: Development and evaluation of improvements to health care in care homes

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ISSN 2044-4230

Summary

This paper is to support further reading and study for people who have seen or would like to see the short film *Today is Monday.* The film was one of the many products of a programme of academic research and shows a day in the life of the specialist unit for the hospital care of people with dementia and delirium that was the subject of the research programme.

The film itself is experienced as a piece of cinematic art and does not provide explicit reference to the research. To provide a link to the research, this paper tells the story of the research from its background, through the development of the unit, to its evaluation. At each stage it makes reference to the main research papers that were published. By providing meaningful access for non-academic or non-specialist viewers to the formal research outputs, it is intended that it helps to explain, to justify and to provide the context of the film and enhance its educational value. This paper does not aim to give a scene by scene explanation of the film.

There is much sadness and unease in the film. However, this paper aims to point out not only some of the aspects of good care that are illustrated in the film, but also to help viewers appreciate the absence of some of the poor aspects of care we have previously observed. This might be necessary as some viewers who are not familiar with hospitals may be unaware of how different the care portrayed in *Today is Monday* is from that delivered in many non-specialist settings. Although *Today is Monday* is not yet freely available for ethical reasons related to consent, access to it can be obtained via the authors for any individual for educational or academic purposes. Information about the development and use of *Today is Monday* will be kept up to date on the website for this Discussion Paper series (http://nottingham.ac.uk/mcop) under the "Impact" tab.

ISSN 2044-4230

Introduction

Today is Monday is a 20 minute film about a specialist unit for people with delirium and dementia in a specialist Medical and Mental Health Unit (MMHU). This unit was developed in the Nottingham University Hospital, in the UK, to deal with the shortcomings of care in general hospitals for people with delirium and dementia.

The footage was taken on the unit over a week or so by a professional film-maker, Owen Davies, with Pippa Foster from the research team. After much debate about a scripted documentary with "talking heads" the research team commissioned a short documentary illustrating the unit and its work with no script, plot or prompts. The film-makers used the footage to create a view of a day in the life of the ward, its staff and patients, beginning in the early hours and ending in the evening, giving glimpses of the stories of some of the patients. The title comes from a short sequence showing a whiteboard on the wall of the unit to orient patients to the day of the week.

The film-makers worked with the ward developers and research team to help illustrate the distinctive innovations of the unit, such as the communication skills in specially-trained ward staff or the use of purposeful activities as part of the therapeutic regime. The film shows the challenges of the care in hospital of very sick people with delirium and dementia, some at the end of their lives.

Formal consent to be filmed was obtained through caregivers of the patients on the ward, and with staff directly, and no-one was recognisably filmed if they or their carers had any objections to the process. Respecting the wishes of many not to be identifiable, the camera angles and points of view were chosen carefully such as by filming people from behind, their hands or legs, or conversations behind curtains, which lends much to the way the film tells its story implicitly rather than explicitly. At the time of writing, the nature of the consent given is that *Today is Monday* is for educational purposes only rather than to be made freely available.

The film was completed during 2013 and, by the beginning of 2014, the film had been seen by more than 750 people throughout the world, including those in the documentary (or their carers), carers of people with dementia, the general public, health and social care professionals, and policy makers. At every showing, without exception, there has been a strong emotional reaction by audiences, often initially stunned into silence or otherwise moved, sometimes to tears.

The film is intended to have several purposes.

- It is a realistic starting point for classroom professional training and development in the skills in the care of older people with delirium and dementia.
- It is a powerful method of bringing home the realities of care of these people in a general hospital, and hence is used as part of the general process of dementia awareness, particularly for those people who have never experienced the hospital care of a person with dementia or delirium.
- It is an aid to "research knowledge mobilisation". The purpose of this paper is to support this process. The Medical and Mental Health Unit illustrated in the film was developed and evaluated with the support of a NHS National Institute for Health Research (NIHR) Programme Grant for Applied Research, the Medical Crises in Older People programme (NIHR-RP-PG-0407-10147, between 2008 and 2013) and an associated NIHR Research for Patient Benefit grant (NIHR PB-PG-0110-21229). This research programme undertook a considerable amount of developmental and evaluative research. We have found that some viewers of the film ask "how did they do that?" and are interested in knowing about the theoretical and practical aspects that brought this unit about, and what was found when it was evaluated . This paper summarises and gives links to much of the development and evaluative work related to the Medical and Mental Health Unit.

Background and context

In fact, the development of the Medical and Mental Health Unit was not only supported by the Medical Crises programme, but also by another research grant - the Better Mental Health study funded by another arm of the NHS National Institute for Health

Research (NIHR), the Service Delivery and Organisation programme (NIHR-SDO-08/1809/227). The Better Mental Health study aimed to describe and explain the care of older people with delirium and dementia in general hospitals - the Medical Crises in Older People programme can be seen as aiming to develop a "solution" to the problems identified in the Better Mental Health study.

Research outputs from the Better Mental Health study provide useful contextual information relevant to the Medical and Mental Health Unit:

The final report of the Better Mental Health study [1] and a short paper in this MCOP Discussion Paper series [2] provide brief summaries of what was known about the prevalence of mental health problems in hospitals and the organisational background. For example, this background work showed that around half of all people who fracture their hips have dementia, about 30% of older people admitted to hospital have or develop delirium, and up to 40% of older people in hospital have dementia: the care of such people is "core hospital business". It is not surprising that there are rarely problems in filling beds on the Medical and Mental Health Unit. The outcomes of these patients are considerably worse than for similar patients without delirium and dementia: in hospital mortality for elderly people with dementia 18% versus 8% for those without, and the median lengths of stays are 11 versus 7 days [3].

The Better Mental Health study looked more closely into the care of older people with delirium and dementia in hospitals by undertaking an interview study of the views and experiences of staff [4], and an observational and interview study of patients and their carers – much of this written up in a number of separate reports about the experiences of carers [5], the challenges of achieving person-centred care [6], and the responses of staff to these patients [7].

Staff were, by and large, ill prepared to deal with this "core hospital business" and referred to the inadequacy of their undergraduate and postgraduate training, and the organisational support in providing good care. Far from being uncaring, they expressed a strong desire to be better trained and supported. Many staff found caring for these patients challenging and, at times, adversely affecting their own health and well-being.

There is a considerable contrast between this view of health care staff and the view obtained from *Today is Monday*, and later in this report we describe the steps that enabled this transformation.

The observational and interview study came up with the overarching notion that an admission to hospital of a person with dementia can be seen as a "disruption to routine", and that the actions and behaviours of patients and their carer could be interpreted as being largely designed to maintain and restore "routine" [8]. Thus, carers would aim to try to keep their loved ones away from hospitals and doctors if at all possible when ill, by compensating by increased input themselves. When their loved ones were in hospital they would aim to deal with them and staff in ways expected to help the restoration of routine – although many found that they were ignored if they tried to explain, for example, that their loved one like to eat standing up, or did not like this or that food. Similarly, the patients themselves were seen to struggle to make sense of their illness and their behaviours could be interpreted as trying to return to routine. For example, wandering could be seen as looking for a familiar routine place, or simply because they were usually routinely active at home).

This "disruption" hypothesis also proposed that restoring routine, when successful, was associated with good outcomes, but that maladaptive responses could lead to poor outcomes. For example, early recognition of a patient's needs as informed by a carer might lead to them settling quicker, being discharged quicker, and returning to normal quicker, and vice versa. The "About Me" nursing document [9] is a tool, illustrated in *Today is Monday*, that was developed to assist ward staff in finding out the relevant facts about patients with dementia. *Today is Monday* can also be interpreted as showing patients and carers experiencing disruptions, and observation of the way staff deal with patients and carers in *Today is Monday* is intended to demonstrate practical examples of good practice. A useful example of the value of the Medical and Mental Unit approach is given by the view of a family carer of a patient cared for on the Unit [10, 11].

While we were doing the Better Mental Health study, in particular the observation and interview studies, we came across carers who were very upset with the care their loved ones had received. We were therefore driven to ask why this happened, and whether a

fuller understanding might lead to something that could be done to reduce or prevent this distress. We proposed a model, the "cycle of discontent" [12] as an example of maladaptive responses to the disruption caused by a hospital admission. The cycle begins with a carer trying to keep the patient at home when they get ill, trying to maintain routine. But eventually the patient is admitted and the carer accompanies or follows them through the emergency department, admission unit and onto the ward. At each step along the way "events" can occur - the patient could fall, or become agitated for example. Also, at each step there is the potential for effective or inadequate information transfer. At each step there is a potential for carer stress to be recognised or to be missed. In the worst cases, events and communication failures occur. At this point the carer can attempt to engage more and get control of the disruption, or could become demoralised and fearful. In these cases we describe the process of "hyper-vigilant monitoring" by carers, such as perusing the nursing charts looking for problems or interrogating other patients on the ward. By this point communication is breaking down and so this process can be one of finding new problems and heaping increasing blame and anger upon staff, and now a vicious cycle can develop with increasing withdrawal and conflicts with staff. Eventually the patient is discharged, but the next time they get ill (and sadly, such patients are inherently medical unstable) the carer is now pre-conditioned and wary of hospitals, with the risk of this becoming a self-fulfilling prophesy. If this model is correct, then early attention to communication including the recognition of carer stress and explanation about events could be helpful in preventing this cycle from developing, and identifying signs of hyper-vigilant monitoring could be useful to intervene at that stage to avoid further escalation. We do not see evidence of this process in *Today is Monday* but we do see early discussion with families about the care of their loved ones.

The Better Mental Health study and the Medical Crises in Older People programme were aligned in the "Better Mental Health cohort study" in which we identified older people with mental health problems when admitted to hospital as a medical emergency, and followed them up [13]. We reported the findings of this cohort study in three key papers:

- In a paper on the prevalence of mental health problems in hospitals [14] we confirmed the prevalence of these problems seen in other studies, but also described in depth the range of concomitant physical problems. For example, in those with mental health problems, 47% were incontinent, 49% needed help with feeding and 44% needed major help to transfer. This illustrates that mental health care needs to be given alongside, and integrated with, usual physical nursing care - requiring a different style of nursing. Psychiatric symptoms were not uncommon (6% had hallucinations, 8% delusions, 21% apathy and 9% moderate or severe agitation/aggression) which further compound the nursing challenge. Some of these features are well illustrated by several of the patients seen in *Today is Monday*.
- It is no accident that family carers are prominent in *Today is Monday*. A paper describing carers [15] revealed how diverse a group they are and how high levels of stress in carers are associated directly with illness in the people for whom they care: high carer strain was seen in 42% (>7 on the Carer Strain Index, a questionnaire), particularly among co-resident carers where high stress was seen in 55%. This implies that carers are appropriate targets for intervention in their own right, not merely insofar that they are important for management of the patient. Effective interventions for carers promise to prevent the negative physical and mental effects of stress as well as permitting them to continue for longer in the caring role, which can sometimes postpone the transfer of the cared-for person to hospital or residential care with consequent costs for the individual or the state. The follow-up part of the cohort study was perhaps the most telling paper [16], as it detailed the range of adverse outcomes that these patients experienced over the six months after admission to hospital. By that time, 31% had died, 42% had been readmitted and 24% of community residents had moved to a care home. Only 31% survived without being readmitted or moving to a care home. *Today is Monday* shows patients who were unlikely to survive and perhaps the most poignant patient story captured in *Today is Monday* cover the experiences of a gentleman being discharged to a new care home that very day.

ISSN 2044-4230

Development

The findings as described in the previous section led us to believe that a whole new system of care would be required, not merely a single intervention such as a drug or a training programme. This justified the development of the Medical and Mental Health Unit. Inspired by the success of in-patient stroke units (which in the mid 20th century were controversially proposed as a means of improving outcome after stroke, and by the end of the 20th century had been proven emphatically to do so [17]) we proposed that a specialist unit for people with delirium and dementia might improve their outcomes. Although a specialist unit would never be able to deal with all people in hospitals with delirium and dementia, such as those necessarily on surgical or other specialist wards, if successful it would act as a demonstration unit for the principles involved as well as providing a service model for the majority.

The principles of the Medical and Mental Health Unit are described in detail elsewhere [18], and in summary are comprised a package of changes across several areas:

- Increased resourcing, especially mental health nursing (*Today is Monday* shows such staff)
- Introducing the philosophy of patient centred care for nursing staff (*Today is Monday* aims to illustrate this, such as the lady who is given her salt, pepper and sherry before she eats her meal)
- Dementia specific education for all ward staff (*Today is Monday* shows staff de-escalating aggressive behaviour, as taught)
- An emphasis on purposeful activity (*Today is Monday* shows patients and staff enjoying themselves playing games and drinking tea, acting both to distract patients from boredom and to help them perform the tasks that are part of their normal routine)
- Environmental change (the whiteboard on which *Today is Monday* was written represents an example of this change, although many viewers of the film may not appreciate the absence of blaring pop music which was banned or intrusive alarms that were silenced, but will see that the ward remained cluttered and noisy).

- Greater family involvement (illustrated at several points in *Today is Monday*)
- Policies and procedures (the use of "About Me", illustrated in the film, is but one example of an innovation introduced in the Unit)
- Medical management (the doctors are seen in the film, managing diabetes for example, but key aspects not shown in the film were the steps taken to reduce the risk of delirium such as a thorough medication review)
- Interface with other agencies, and enhancing staff morale through support and mentorship, developing a research and continuing development culture and improving the leadership and management structure (aspects that were literally behind the scenes and not evident in *Today is Monday*)

The development paper also makes it clear that these changes did not come free: the extra staff cost £280,000 per year in 2009. It may be that the trite slogan "compassion costs nothing" is true, but to change the system sufficiently to make a difference, we argued that a significant amount of investment was necessary. In our case, the negotiations with the commissioners who were responsible for funding this rested on the case that this investment was required to undertake research. For those wishing to make similar development outside of a research context, the discussions with funders are likely to rest upon the evidence of benefit and the economic consequences.

Evaluation

The key paper about the evaluation of the Medical and Mental Health Unit gave the results of a randomised controlled trial comparing the clinical outcomes of a group of 300 patients managed on the Medical and Mental Health Unit and a similar number on other, ordinary hospital wards [19]. Many outcomes were little different between the groups: mortality, length of stay, cognition disability and behaviour were similar in the two groups. There was a trend towards fewer people from the Medical and Mental Health Unit moving into long term care than in the group given ordinary care (20% vs 28%), but this could have arisen by chance. One of the many outcome measures used in the trial was derived from painstaking structured observations of patients on the Medical and Mental Health Unit and matched patients on other wards, describing their behaviour, level of engagement and whether they experienced positive or negative interactions (or

none). This, in effect, measured the quality of care and experience of patients. Patients on the Medical and Mental Health Unit were unequivocally more engaged, appeared in better spirits and had more positive encounters than those on other wards -patients on the specialist unit spent significantly more time with positive mood or engagement (79% v 68%) and experienced more staff interactions that met their emotional and psychological needs (median 4 v 1 per observation). Another outcome measure in the study was carer satisfaction which, again, was strongly in favour of the unit. More family carers were satisfied with care (overall 91% v 83%), and severe dissatisfaction was reduced (5% v 10%). Since *Today is Monday* pictured life on the Medical and Mental Health Unit only, viewers are not afforded a look at what care was like elsewhere, and this is why the results of a rigorously designed scientific study was needed to be able to demonstrate that the quality of care and satisfaction with it were truly better.

The research team would never aim to suggest that care on the Medical and Mental Health Unit is ideal, and some expert viewers of the film have commented critically about how aspects of care and communication might have been better. Mindful of this, we used this trial also as an opportunity to identify the next priorities for research in this area. An example is a paper written about the carers in this study [20]. Despite demonstrating that carer satisfaction was better for those managed on the Medical and Mental Health Unit, carers' experiences were far from ideal and we detected an astounding and pervasive need amongst carers for discussion, support and information. The involvement of carers in day to day acute care practice can still be enhanced; *Today is Monday* shows some forms of involvement by carers in feeding and comforting relatives.

At the point of writing this report, the economic results of the study have not been published. Whilst not wishing to report extensively on un-published material, we can state that analyses being prepared for publication indicate that the Medical and Mental Health Unit was approximately cost neutral from the hospital's perspective (there was a small but not significant reduction in length of stay which offset the costs of the intervention) but was highly likely to be cost effective using a cost utility analysis (in part due to the non-significant reduction in care home use). At the time of writing, several

other papers are in preparation for publication, such as a paper about staff experiences (contrasting with the findings of the Better Mental Health staff study). All papers listed in this document, and all those that will subsequently be published, will be listed on the Medical Crises in Older People Discussion Series site (www.nottingham.ac.uk/mcop) under the tab for "Impact" and the subsection "Journal contributions".

Summary

This document provides viewers of *Today is Monday* with a brief description of the research and development work that went on before and during the events that are shown in the film. We hope that some viewers who have responded to the film with feelings of empathy, sadness, anger and hope will also be challenged to ask what can be done to replicate this experimental ward or to improve upon it. We trust that by providing access to the scientific underpinnings of the Medical and Mental Health Unit, these people can feel empowered and authorised to bring about change whether as policy makers, commissioners or providers: the Unit proves that person-centred care is possible even in difficult circumstances, and in the best cinematic tradition *Today is Monday* goes beyond story-telling to help us all understand what it feels like to be in an acute hospital setting as a carer or a patient with cognitive impairment.

Funding acknowledgment and disclaimer

This paper presents independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research funding scheme (RP-PG-0407-10147). The views expressed in this paper are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

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