

ABSTRACT

In this article, we present the experiences of discharging against medical advice from the perspectives of 17 hospital and community based healthcare practitioners, and 16 patients, and relatives from a range of medical and surgical wards. Semi-structured, in-depth interviews were conducted and thematically analysed. We identified that practitioners, patients and relatives frequently expressed empathy for each other during the interviews and discharge against medical advice was presented as a way for patients to have control over their health. Contrary to predominantly negative framings that highlight increased mortality and morbidity, and portray people who discharge against medical advice as poor decision makers, we conclude discharge against medical advice can be framed positively. It can be an opportunity to empathise, empower, and care. We recommend that the vocabulary used in hospital discharge against medical advice policies and documents should be updated to reflect a culture of medicine that values patient autonomy, patient-centeredness, and shared decision-making.

INTRODUCTION

Self-discharge or discharge against medical advice (DAMA) is described as when a “patient chooses to leave the hospital before the treating physician recommends discharge”

(Alfandre, 2009). Approximately 2-3% of patients discharge themselves from hospital against medical advice each year in the UK and US, and recent figures show it is increasing annually (Bolton NHS Foundation Trust, 2016; Wales NHS University Health Board, 2016; Warriner, 2011). DAMA attracts significant, predominately disparaging attention.

References by clinical researchers to increased morbidity, mortality and readmission rates, portrays DAMA as damaging to patients' health (Fiscella, Meldrum & Barnett, 2007; Hwang, Li, Gupta, Chien & Martin, 2003; Southern, Nahvi & Arnsten, 2010) and patients who DAMA have been depicted in social media by healthcare practitioners, such as 'The Secret Doctor' and 'Illusions of Autonomy', as poor decision-makers. Thus, research studies largely recommend interventions to reduce DAMA (Edwards, Markert & Bricker, 2013; Moyses, 2004).

DAMA is an emotive issue that evokes a range of negative responses from healthcare practitioners (Alfandre, 2009). Staff frequently report frustration at the time-intensive nature of managing a patient's decision to DAMA (Berger, 2008). Staff may also feel their clinical judgement has been challenged, their authority undermined, or that they have failed in some way when a patient self-discharges (Windish & Ratanawongsa, 2008). Figures suggest that self-discharge financially impacts upon already strained healthcare systems with patients who DAMA costing over 50% more than expected of comparable patients, and readmissions to hospital costing £300 million in the UK and \$2.6 billion in the US, of which patients who DAMA form a significant proportion (Onukwughu et al, 2012; Sg2, 2016).

Nevertheless, in the UK, patients have the legal right to determine if they wish to stay in hospital or not, providing they are over 16 years of age and not detained under the Mental Health Act 1983. If they have mental capacity e.g. they can understand the risk, benefits and consequences of their decision to discharge themselves against medical advice, their autonomy must be respected even when others may think their decision is unwise (section 1(4) MCA 2005). However, while there are no standard guidelines outlining the criteria for defining DAMA, it is considered best practice to document that the patient left the hospital despite an explicit clinical recommendation to the contrary. Even so, it is important to note that whilst DAMA forms used by most hospitals were designed to relieve culpability from litigation that may arise after a poor outcome, by and large these documents do not contain all the necessary details to confer legal protection (Henson and Vickery, 2005). These conflicting legal positions – of the necessity to respect autonomy and the impossibility of absolving professional responsibility – place healthcare practitioners in an ambiguous professional position.

There are multiple reasons why patients discharge themselves from hospital including long waiting times, poor communication, lack of medical insurance and dissatisfaction with care (Alfandre, 2009; Onukwugha et al, 2012). As such, patients are viewed as problematic or non-compliant, and healthcare practitioners and the healthcare system are deemed too rigid or insensitive to the needs of those it serves (Stern, Silverman, Smith & Stern, 2011; Weingart, Davis & Philips, 1998). The language used to describe the act, apparent on the paperwork given to people who DAMA i.e. discharge *against* medical advice, an

unauthorised discharge, reinforces this view implying they have acted inappropriately, and their decision requires explicit justification (Alfandre, 2013).

Furthermore, such language suggests an outdated paternalistic approach in conflict with the contemporary culture of shared decision-making (SDM) and the aim of patient-centered care (Clark, Abbott & Adyanthaya, 2014). For practitioners working in the UK, the General Medical Council mandates that “the patient is the first concern” (GMC, 2006) and the disparities in power between patient and doctor is deemed by some to have narrowed (Bury, 2004). SDM is an example of this that acknowledges both the doctor and patient as experts, the doctor on diseases and treatments and the patient on their needs and preferences. In practice, SDM means all the options available to patients are explored and decisions about their care are made in partnership. As Bury (2004) explains, practitioners must now practise in an environment where their authority is not automatically accepted. Yet, the current approach to patients wanting to DAMA does not embrace a modern healthcare culture, nor reflect a founding tenet of healthcare ethics; the right of the patient to self-determination. However, honoring patient autonomy in SDM sometimes can conflict with practitioners' other ethical obligations to act in ways that benefit the patient, and avoid doing harm. As noted by Feinberg et al “When a patient leaves hospital under circumstances that do not seem ideal, the focus should be on establishing the patient’s capacity and arranging the safest plan for follow up, rather than creating conflict.” Yet, the current discursive framing of DAMA constructs an adversarial situation in which staff hold an authoritative, knowledgeable position and patients occupy a position wherein their reasoning is questioned, and their identity labelled as demanding (Jerrard & Chasm, 2011).

This largely negative positioning of patients who DAMA is exacerbated by previous research that has focused on certain demographic populations, namely young, male, and socially disadvantaged, or involved with substance misuse, or from ethnic minorities, all of whom are considered more likely to DAMA (Aliyu, 2002; Ibrahim, Kwoh & Krishnan, 2007; Weingart, Davis & Phillips, 1998). In this article, we look beyond demographic factors in order to challenge the negative framing of DAMA. We claim DAMA can be an occasion to empathise, empower, and care.

METHODS

Our qualitative study involved 33 in-depth, semi-structured interviews conducted between February 2013 and April 2014 in order to understand healthcare practitioners, patients and relatives perspectives of DAMA. Participants included 16 people across England who had experienced DAMA from the perspectives of a patient and/or a relative (see Table 1), and 17 hospital and community based practitioners located in two National Health Service (NHS) Trusts based in the North of England, including General Practitioners (4), nurses (3), junior (6) and senior doctors (4). The hospital trusts were identified because of their differences in the category of hospitals i.e. general, district, the location of the hospitals i.e. large inner city, small rural town, the size of patient and staff populations, and the range of medical specialities provided, therefore enabling a wide range of experiences to be captured.

Participants were recruited through advertising the study within NHS Trusts, patient advocacy groups and citizen activist groups, such as Healthwatch UK, CancerVoices.

Participants were self-selecting and it is not possible therefore to know how many chose not to participate in the study. Practitioners were included in the study if they had been

involved in caring for patients or interacting with relatives who wished to DAMA, irrespective of the patients' conditions or the practitioners' medical specialities. Patients who DAMA and/or their relatives were included in the study, irrespective of the reason for being in hospital, the location of the hospital, or date of DAMA. The eligibility criteria to participate in the study were intentionally broad given that people who DAMA are a small, hard-to-reach population, although we accept this has limited the generalisability of our findings.

Nevertheless, Holstein and Gubrium (1995) argue that a qualitative sampling process can extend into the data collection phase in order to respond to the direction of the research. Our aim was not to gather a representative sample as, consistent with a constructivist epistemology, we recognise there is not only one objective truth to be told (Berger & Luckmann, 1966), rather DAMA can be understood in multiple ways. For Kvale (1996) reality is created through meanings and as we sought to elucidate the variety of meanings DAMA holds we therefore aimed to include a multiplicity of voices in our study. Accordingly, when participants suggested other potential participants, such as junior doctors, general practitioners, or specific practitioners who had experienced a challenging case, these were followed up when feasible.

Procedurally, ethical considerations extended to gaining approval from three sources: the University institution, the NHS, and the two NHS Trusts. Every participant was sent a consent form and a participant information sheet via email before the interview took place to ensure they were aware what the interview involved and give them the opportunity to ask any questions regarding the study or their participation. It was explained to participants that

they could withdraw their consent at any point throughout the interview. Limited demographic details of the participants are provided to respect participants' anonymity.

The interview guide was compiled by LM and DW, and was informed by the literature review and research aims. In keeping with the semi-structured, in-depth nature of the interviews, the guide contained a mixture of direct questions on specific topics and open questions that enabled participants the opportunity to raise issues around DAMA that were significant and relevant to them but might not have been considered previously. Interviews focused upon eliciting how participants experienced the process of DAMA (see Table 2). Whilst healthcare practitioners began their accounts describing challenging experiences involving people with addiction or lacking capacity, when prompted, all participants recalled positive experiences of DAMA, and it is this subset of data on which we report. Interviews were conducted either in person or over the phone by LM and lasted between 45 – 60 minutes each. All interviews were tape-recorded and transcribed.

Transcripts were thematically coded by LM and DW using the qualitative computer package, Nvivo (Attride-Stirling, 2001). Initially, the codes were based upon very broad themes relating to the processes and practices surrounding DAMA. Coding at this level highlighted differing perceptions of DAMA, and consequently new codes were developed to encapsulate the relationships and interactions between patients, relatives, and healthcare practitioners. During the coding phase of the data, we discerned that individual participants adopted multiple identities and positioned themselves differently throughout the interview (Holstein & Gubrium, 1995) by using statements '...I'm also a patient myself...' or '...as someone who knows only too well what hospitals are like....'. This observation drew our

attention to how participants discursively avoided an adversarial framing of DAMA in which patients and relatives are pitted against healthcare professionals. This perception became an important step in our analysis, informing the themes and overall argument as it is an account absent from the existing literature. Further analysis then involved discussion by all three authors of how specific data extracts within the themes should be interpreted and presented. The different professional identities of the three authors (socio-ethicist, healthcare professional, social scientist) brought different, but overlapping, perspectives to bear on the data. Timmermans and Tavory (2012) acknowledge that, as researchers, we always occupy a certain position that colours our vision. Positions, however, are complex in that we see through specific life histories as well as the lenses of professional training and theoretical learning. Consequently, our analysis brings together overlapping understandings of healthcare practice, ethics, and social interaction. Thus, data were situated and analysed in relation to contemporary health care ethics and values that prioritise concepts of autonomy, empowerment and patient-centredness, but also with sensitivity to the discursive framing of experiences that sought to avoid the allocation of blame. This iterative approach to analysis led to refinement of the coding (Seale and Kelly, 1998) as well as developing the nuance of our argument.

RESULTS

I understand

Healthcare practitioners, and patients and relatives frequently expressed empathy for each other during the interviews. When asked why they thought people wished to discharge themselves or their relatives against medical advice, practitioners demonstrated some

insight into patients' experiences of the hospital environment. A head of emergency medicine at a district hospital explained,

...they're [patients] scared of what will go on in hospital...It's okay to be scared.

Hospital isn't a very nice place... (Practitioner)

Below, a nurse from a large medical acute unit at a general hospital elaborated upon why hospitals may be unpleasant environments,

...we're [staff] waking them [patients] up in the middle of the night to check their observations, we've got patients coming and going and monitors going off, you get why somebody would much rather be at home in their own bed using their own facilities. (Practitioner)

A registrar in a cardiology ward at a general hospital also described the hospital environment as unpleasant at times when claiming that some patients are justified in their decision to discharge themselves against medical advice,

Most people have a level of patience but that patience is really tested in NHS wards...because they're busy. You can't sleep. There's people screaming. There's patients wandering...it's a very uncomfortable environment. And if patients are ill where they want to be is at home where they feel most comfortable. (Practitioner)

Understanding that patients may find hospitals intimidating, wearisome, or disruptive enabled staff to appreciate the rationality of peoples' desire to leave hospital. A junior doctor two years post medical school on placement at a district hospital discussed the difficulty in challenging a patient's or relative's decision to DAMA, particularly when remaining in hospital would have minimal improvement to a patient's wellbeing,

I could appreciate that they were very fed up and I could appreciate why they wanted to leave. There have been a couple where I've basically thought they were right. (Practitioner)

Likewise, a general practitioner based at a practice in Cumbria noted that in the context of adult patients with capacity, people should not always be deterred from discharging against medical advice,

...half the time when they're wanting to, they're not actually being unreasonable.

Given the same set of circumstances I might want to do exactly what they're doing.

(Practitioner)

Here, practitioners positioned themselves as fellow patients, avoiding an oppositional stance and interpreting the decision to DAMA as reasonable.

Similarly, patients and relatives demonstrated empathy for healthcare practitioners, appreciating their ability to deliver care in difficult circumstances. Patients and relatives frequently commented on the time pressures placed on staff, and how these were exacerbated by staff shortages. This awareness enabled patients and relatives to make sense of the lapses in care they experienced or observed. Rather than blaming individual practitioners for poor care, the systems and circumstances of hospital care were perceived as problematic. Never were staff deemed as having control over the circumstances within which they worked as the following quotes from two women who discharged themselves illustrate:

I could have quite easily have asked somebody to change my sheets. But they were very busy and...you appreciate that they haven't got that many staff on. (Patient)

...because they were so overworked and stressed they got a bit, you know, they were professional but they weren't kind because they were too stressed. (Patient)

The constraints upon practitioners were also apparent when patients and relatives discussed the implications of a decision to DAMA. Leaving hospital was framed positively as it released staff time and NHS resources as one woman explained when she discharged herself after having surgery and another woman discharged herself from a general medical ward:

I did feel sorry for them, yeah...I thought if I come out there will be one less bed to look after. (Patient)

I think you're almost doing them a favour to release the bed up...Why would I want to have to use some of the nurses' time up in the night for them to come and check my bed and make sure I'm there. (Patient)

These patients saw themselves as reducing the workload of hospital staff and presented the patient-staff relationship as a sympathetic one, constructed around appreciation and understanding.

I care

Healthcare practitioners, patients and relatives positioned DAMA as an expression of patients' distress at their circumstances. Viewing DAMA in this way generates positive outcomes for patients and staff in that it highlights a hitherto unidentified need and initiates communication between healthcare practitioners and patients. Essentially, it is an attempt to initiate discussion, rather than criticism. An experienced nurse on a cardiology ward in a general hospital described how he responds to a request of leave hospital,

We initially will talk to the patients and try and find out why they want to leave...See if there's anything else going on. I mean, I've met people who when you get to the bottom of it they've got problems at home. (Practitioner)

Similarly, when a junior doctor at a district hospital discussed ways how DAMA could be reduced and prevented in some case, he proposed,

You just need to spend a few extra minutes to sit down and talk with them. I think that's a big issue is communication. So I think sometimes you can talk them round. (Practitioner)

The source of distress was frequently focused upon during the interviews with patients, relatives and practitioners; hospitals were portrayed as uncomfortable, anxiety-provoking environments. Contrary to the adversarial framing discussed above, patients stressed that their reasons for DAMA related to the distress of living in a hospital environment when feeling unwell, rather than poor care per se as the quotes below from participants who had discharged themselves or a relative on separate occasions illustrate:

It's an indication that patients aren't happy in that environment. (Relative)

I don't like being in hospital. I didn't like being in the ward environment even though it was actually very good. You absolutely couldn't criticise it. The staff were very good...So as long as I felt safe I just preferred to leave really. (Patient)

Understanding DAMA in this way meant some healthcare practitioners acknowledged the need to provide alternatives to hospital admission when feasible or to work around the inflexibility of hospital, as a senior doctor at a general hospital in the North of England explains,

But there's others who for often good psychological reasons often don't like to be in hospital...And in those cases we try and liaise with the GPs to make sure they get some follow up. (Practitioner)

Similarly, a nurse on a cardiology ward described how he adapted his practices to accommodate the needs of patients wanting to DAMA,

...we'll try and reorganise things...and say this is an outpatient's appointment instead of an inpatient. (Practitioner)

By these actions, staff acknowledged patients' concerns, and demonstrated appreciation for patients' emotional well-being, as well as their continuing commitment to care after discharge. Practitioners viewed such actions as part of their caring responsibilities, thereby casting doubt over the perception of DAMA as always being a distracting and untimely termination of care. Instead, staff demonstrated care towards patients, and in turn, patients felt cared for by practitioners, constructing a positive framing of DAMA.

Patients matter

The matter of control within a hospital environment and in determining care figured strongly in all participants' accounts of DAMA. Staff acknowledged hospital processes as restrictive, suppressing patients' abilities to be active participants in their care and positioned DAMA as a response to the lack of control patients experienced. Here, patients who DAMA were described as 'disempowered' rather than 'difficult':

...with our diabetic patients who are self-managing for 365 days a year to then come into hospital and then for everything to be taken away from them, that can be very disempowering. So, yeah, I can absolutely see that the decision to self-discharge would be about wrestling back the control to themselves. (Practitioner)

Sometimes it's lack of empowerment that makes them want to do that in the first place if they don't feel that they've got any control over what's happening to them.

(Practitioner)

Similarly, a woman who discharged herself after being in hospital for three days after giving birth highlighted the significance of control when making a decision to leave,

Because the important thing for me was to be in control of what I was doing not just be lying on a bed. (Patient)

Viewing DAMA as a way of reclaiming control redefines the act of DAMA and the identity of the patient. When viewed this way, DAMA became a mechanism for the voicing and hearing of patients' opinions. It enabled patients to reclaim a sense of control at a time of distress and vulnerability. Therefore, staff and patients were reluctant that DAMA be seen as something to be avoided, instead emphasising the importance of patients having control over their health.

DISCUSSION AND CONCLUSIONS

The dominant discourse within the existing literature largely portrays patients who DAMA as difficult and irrational, whilst practitioners are deemed uncaring, and healthcare systems are considered unwieldy. Yet, our discussions with healthcare practitioners, patients and relatives, have shown that DAMA can be framed positively. Practitioners identified with patients, demonstrating insight into how patients experience the hospital environment. Equally, patients and relatives readily recognised the factors that hindered staff and in turn, the decision to DAMA was one that would in some way benefit practitioners, thereby challenging previous portrayals of people who DAMA as problematic and demanding.

A request to leave hospital enabled patients and relatives to voice their concerns and created a space for practitioners to identify patients' needs, modify their care, and communicate their compassion towards patients. Canary and Wilkins (2017) found that discharge procedures more generally do not foster open communication and that patients and relatives experienced lack of communication as a particular problem. They argue that post-discharge communication represents a critical issue for improving discharge experiences. This supports a key argument of our analysis, that is, by taking an alternative view of DAMA, one characterised by empathy and empowerment, DAMA procedures become an opportunity to demonstrate compassion towards patients, when faced with their desire to terminate care.

In the UK, hospital procedures for managing DAMA encourage nurses and doctors to caution against it, implicitly persuading patients to stay, and therefore adopting an inherently paternalistic position. Such a predisposition works against seeking to understand the reasons why a patient or relative wishes to DAMA, respecting a patient's autonomy, and is out of step with contemporary values of patient-centred healthcare. Furthermore, the legal status of DAMA forms and procedures is ambiguous. Henson and Vickery (2005) note that unless DAMA documentation contains an assessment of the patient's capacity, confirmation of the patient's awareness of the risks of leaving hospital and the circumstances under which they should return, then such forms may not be fit for the purpose of protecting the practitioners involved from criticism and legal redress (and only one out of the eight forms they reviewed contained such details). In contrast, it is worth noting the more general medical protection position statement that "it is unlikely that a

doctor will be legitimately criticised if a competent patient has made an informed decision to pursue a particular course of action” (Medical Protection Society, 2015).

Given this ambiguous legal footing, and in line with contemporary healthcare values that increasingly prioritise patient autonomy, one implication arising from our reformulation of DAMA is that it may not always be considered inappropriate for patients or relatives to DAMA. In this article, we have demonstrated that there are occasions when practitioners can perceive the decision to DAMA as reasonable, and in turn, it challenges the portrayal of people who DAMA as poor decision-makers as depicted on social media. Instead, it may be a rational decision and therefore provides an opportunity for practitioners to formulate a more patient-centred plan of care. Furthermore, viewing DAMA as a rational decision raises the question of whether patients should have been discharged sooner, or even not admitted in the first place. Indeed, in an era when physicians, and increasingly patients and relatives, are becoming mindful of the risks of ‘over-diagnosis’ and ‘too much medicine’ (Moynihan et al, 2013) it is perhaps understandable that patients and relatives fear the consequences and complications arising from admission to hospital, which could account for an increase in the rate of DAMA. Research is needed to explore the reasons why patients who DAMA were admitted, and whether their admission could have been avoided or shortened.

Proposing that a positive view of DAMA is possible does not erase the occasions when lapses in care are experienced, or suggest that DAMA is always appropriate. Instead, we suggest that the *reasons* for the care delivered and received, and the decision made need not necessarily be read as threatening or critical as is currently depicted in the literature

(Alfandre, 2006; Onukwugha et al, 2012; Windish & Ratanawongsa, 2008). An area for future research that follows from our reformulation of DAMA is how it might reframe the actions of those patients most likely to DAMA and who are potentially most vulnerable – young, male, and socially disadvantaged, or involved in substance misuse, or from ethnic minorities – thereby creating possibilities to demonstrate empathy, empowerment, and compassion.

Accepting the limitations of our findings – small sample size, limited demographic details, and self-selecting participants – a number of recommendations for medical practice arise. Firstly, healthcare practitioners should receive training on shared decision-making in relation to DAMA to avoid unconsciously adopting the predominantly disparaging perspective. Secondly, hospital documentation should not be worded to “persuade” patients to stay, as a priority, but instead, they should explore patients’ and relatives’ rationales when wishing to DAMA and view it as an opportunity to demonstrate compassion and not automatically assume that remaining in hospital is the most appropriate outcome. Thirdly, language used by policy makers to discuss and document DAMA – *against* medical advice, and *unauthorised* discharge – has failed to keep pace with contemporary medical practice, which values patient- centeredness, and where patient autonomy is respected and medical paternalism is frowned upon. This shift in the culture of medicine should be reflected in the vocabulary used in hospital policies, and documents relating to DAMA.

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The authors declare that there are no conflicts of interests

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