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Supporting unpaid carers

ABOUT THE RESEARCH

When an individual's mental health problems require them to be detained under the Mental Health Act (1983) (MHA) for assessment and/or treatment, it is important that they maintain contact with their family, friends and communities as these are often helpful for their wellbeing. Maintaining these relationships is also important to their family and friends ('carers').

Section 17 MHA is a provision for temporary leave from hospital. This may be escorted leave so that the individual is accompanied by a carer or member of hospital staff.

However, carers are not always involved in meetings and decisions around s.17 leave, even where they are expected to visit or to take care of someone during the leave. A recent small-scale study found that carers of people on s.17 leave struggled; most felt unsupported by practitioners and under-involved in decision-making.

AIMS AND OBJECTIVES

The study aimed to:

- Explore how to better support unpaid carers before, during and after s.17 leave;
- Develop a s.17 leave standard (guidance) to improve the communication with, and support provided to, unpaid carers before, during and after s.17 leave;
- Test the s.17 leave standard for signals of efficacy by exploring how mental health services implement the standard and the experience of this for practitioners, managers and carers; and
- Explore the indicative outcomes (the 'signals of efficacy') of the s.17 leave standard for carers.

METHODS

The study constituted:

- A scoping review of interventions that support unpaid carers of adult mental health inpatients to identify an evidence base for the use of particular interventions that support carers.
- Phase 1: Semi-structured interviews and focus groups with carers (n=14),

practitioners (n=15) and Responsible Clinicians (n=4) to explore their views on what involvement and support around s.17 leave carers want, what works well, barriers and facilitators, and what practitioners feel is feasible in practice.

- Phase 2: A non-randomised controlled study to test the s.17 standard for signals of efficacy. Intervention wards (implementing the s.17 standard) and control wards (business as usual) were recruited from each of six NHS trusts. Structured telephone interviews were conducted with carers at three time points: 1) following the patient's admission to hospital under s.2 or s.3 of the Mental Health Act (1983); 2) within two weeks of the patient experiencing s.17 leave with the carer; and 3) six months following baseline. Interviews included a series of outcome measures, plus a qualitative element in the second interview. Due to low carer recruitment, analysis of the quantitative measures was not undertaken. Carers of patients detained in an intervention ward who supported s.17 leave before the baseline interview could be undertaken, were invited to take part in a one-off qualitative interview to discuss their experiences of s.17 leave. A total of 13 carers were interviewed for phase 2.

- Practitioners working on intervention wards were invited to take part in an interview or to complete an online survey to share their experiences of how the s.17 standard had been used in practice and the barriers and facilitators to implementation. 13 practitioners on intervention wards completed an interview/survey.

- Research, clinical and/or managerial (RCM) staff with experience of undertaking research with carers and/or implementing new interventions in inpatient wards were invited to take part in an interview or complete an anonymous online survey. 108 RCM staff completed an interview/survey.

The project advisory group included unpaid carers of people with mental health problems and experience of giving support during s.17 leave, people with lived experience of detention under the Mental Health Act and s.17 leave with unpaid carers, practitioners, researchers and representatives from carer organisations and the Department of Health and Social Care.

The advisory group were involved with: the ethics application; review of data from phase 1; the development of the s.17 standard; wording of the consent forms, information sheets and other documentation; piloting of interviews; the content and visual elements of recruitment materials (including posters), strategies to engage ward staff, recruit carers and implement the s.17 standard; and the design and content of materials including an information leaflet for carers and guidance document for practitioners.

FINDINGS

The scoping review conducted during phase 1 of the study aimed to synthesise the peer-reviewed literature evaluating the impact or outcomes of brief interventions for unpaid carers of adult mental health inpatients, identify transferable lessons for evidenced-informed practice, and establish future research priorities.

Five types of interventions were identified, those that aimed to: 1) increase carer involvement in inpatient care; 2) facilitate

organisational change to increase carer support and involvement; 3) provide carers with support; 4) deliver psychoeducation and offer support; and 5) reduce carer stress and improve coping skills.

The review identified that whilst evidence of intervention effectiveness was promising, the quality of studies was generally weak and thus concluded that more research is needed to develop an evidence-informed approach to supporting carers during inpatient stays. The scoping review also highlighted the dearth of research focused on s.17 leave in the UK, and also the broader lack of research on working with carers during inpatient admissions.

In phase 1, interviews were conducted with 14 carers and 19 practitioners (including four Responsible Clinicians who have overall responsibility for care and treatment for service users being assessed and treated under the Mental Health Act). Carer participants were aged 40 years or older; more than half were female; and all defined as white British. Years in the caring role ranged from less than one year to over 16 years.

Carers were the partner or parent of the patient. Practitioner participants were aged 25-69 years; mostly female (n=15); and White British (n=15). Almost half were nurses (n=9), others included social workers, occupational therapists, psychologists, psychiatrists and healthcare assistants.

The vast majority had experience of working on inpatient wards (n=17), while two-thirds also had experience of working in the community (n=13). Experience of working in mental health services ranged from 0-5 to 16+ years. Four practitioners, at least one from each site, were RCs with 1-13 years' experience in the role.

Three key themes were identified:

- carers' need for support and issues surrounding the provision of support;
- challenges around staff and carers working together, in particular around communication, planning and feedback; and
- the lack of a consistent approach toward the involvement of carers around s.17 leave resulting in confusion and uncertainty for carers and staff alike.

Permeating all themes was a lack of resources presenting as under-staffing, high demands on existing staff, and lack of time and capacity to work and communicate with carers.

Underpinning this demand is the medical model's focus on individual symptoms rather than the importance of wider support and the absence of a focus on wider social and environmental factors that impact health and mental health.

Nevertheless, the medical model and lack of resource did not prevent some practitioners positively involving carers and some carers reporting positive experiences of involvement and support around s.17 leave. The challenge of resourcing, notably staff shortages, impacted on staff time to communicate with carers about s.17 leave, planning s.17 leave, supporting carers following difficult experiences of leave and obtaining carer feedback following leave.

However, not all challenges were resource-dependent. Some carers felt staff ignored or did not value them, while some practitioners acknowledged a lack of confidence in speaking with carers.
Steps to improve carer support and involvement could thus include training for staff about the benefits of working with

and having difficult conversations with carers, information for carers about s.17 leave, and clear, national guidance setting out a consistent approach for practitioners to work with carers around s.17 leave. Such steps could improve communication and staff-carer relationships, carer wellbeing, and potentially carer-patient relations, to the benefit of all parties.

The 'S.17 Leave Standard', was developed out of the research findings from phase 1 and refined by the research team and the project advisory group. The Standard, a guidance document, consists of 10 steps for practitioners to follow to increase and encourage greater involvement and support of carers around s.17 leave.

The Standard covers the need for staff training to improve understanding of the importance of working with carers in general and specifically around s.17 leave, identifying and responding to carer support needs, discussing s.17 leave with carers and answering any questions they may have, involving carers in planning s.17 leave, agreeing any changes to leave with carers ahead of the leave, seeking feedback from carers following leave, and supporting carers following a difficult leave experience

The Standard thus aimed to offer the support and involvement that carers said they wanted and that practitioners felt was feasible in practice. The Standard was articulated in a practice guidance manual to assist practitioners to embed it in their practice.

Phase 2 aimed to test the feasibility of the s.17 leave standard, to explore the extent to which the Standard makes a difference in practice and the extent to which it is feasible in a context of staff shortages and resourcing issues. However, recruitment and implementation of the intervention proved challenging. In particular, Covid-19 and associated lockdowns had a significant impact on the study as wards were locked down for periods of time, thus fewer people were admitted to the wards reducing the potential number of unpaid carers that could be recruited to the study.

Also, s.17 leave was not permitted which reduced the number of carers with experience of leave.

Inadvertently, therefore, this phase of the study explored the challenges around implementing an intervention in inpatient settings and the perceived challenges of undertaking research with unpaid carers of people in inpatient settings.

Practitioners explained that they could not prioritise implementing the intervention due to:

- staffing shortages (with vacancies and staff sickness);
- high levels of acuity on the ward (and thus higher patient demand);
- managing the impact of Covid-19 outbreaks and national/local/ward level lockdowns on patients and staff;
- access to carers, including carer non-attendance on the ward, carers' lack of availability due to other commitments, and carers not keeping wards updated with changes of contact details; and
- lack of time and resource with which to involve and support carers.

Research, clinical and/or managerial staff with experience of trying to implement an intervention in an inpatient setting and/or undertake research with carers in an inpatient setting identified challenges of:

- resourcing (in terms of the physical constraints such as time, workload and competing priorities facing practitioners and the psychological barriers such as limited capacity to absorb new

requirements);
- engagement (where staff did not prioritise engaging in tasks that were not seen to immediately benefit the patient or the staff group, linked to limited resourcing and the culture of the ward);
- engageability (the view that successful implementation of an intervention is an issue of research design, with researchers playing a pivotal role in facilitating the research and the aim that research should be viewed not as transitory but as anticipated to have a lasting impact on practice approaches which correspondingly requires practice input); and
- carer marginalisation (the view that engaging carers in research was challenged by external resource demands such as time and competing priorities), internal psychological capability to engage with research in the stressful context of hospital admission and the need for research to be flexible and adaptable to facilitate engagement.

Limitations

The main limitation during phase 2 of the study was the challenge of carer recruitment which ultimately meant that there was insufficient data to analyse outcome measures for carers. Carer recruitment was largely impacted by (a) the impact of Covid-19 and associated lockdowns on hospital admissions, limits on granting s.17 leave and associated recruitment difficulties; and (b) reliance on gatekeepers, as carers were being invited to take part in the study at ward round at the same time that s.17 leave was being arranged, thus there was insufficient time to recruit and consent carers and undertake baseline interviews before s.17 leave took place.

Other limitations include the s.17 standard not being implemented fully on intervention wards due to staff shortages, high levels of acuity on the wards, access to carers and resourcing; the low number of practitioner interviews, again largely due to staff shortages.

CONCLUSIONS & IMPLICATIONS

There is a dearth of research on supporting and involving carers around s.17 leave in the UK, and more broadly a lack of research on working with carers during inpatient admissions.

The challenge of resourcing, notably staff shortages, impacted on staff time to communicate with carers about s.17 leave, planning s.17 leave, supporting carers following difficult experiences of leave and obtaining carer feedback following leave.

However, not all challenges were resource-dependent. Some carers felt staff ignored or did not value them, while some practitioners acknowledged a lack of confidence in speaking with carers. Steps to improve carer support and involvement could thus include training for staff about the benefits of working with and having difficult conversations with carers, information for carers about s.17 leave, and clear, national guidance setting out a consistent approach for practitioners to work with carers around s.17 leave. Such steps could improve communication and staff-carer relationships, carer wellbeing, and potentially carer-patient relations, to the benefit of all parties.

The conclusions from phase 2 of the study echo and expand on those from phase 1. Practitioners struggled to prioritise working with carers and implementing the s.17 leave standard into their daily practice due to resourcing issues, namely lack of time and resource with which to involve and support carers due to staffing shortages; high levels of acuity on the ward; and

managing the impact of covid-19 outbreaks and lockdowns on patients and staff. Increased staffing and resourcing would help with all aspects. Increased resourcing in mental health services more broadly could reduce demand for inpatient care and/or mean that there are lower levels of acuity on the wards, thus providing staff with the time and resource to work with carers and to implement new interventions. This would also give staff the psychological capacity to do this.

Tackling the social determinants of health and mental health would also reduce the need for mental health support across society.

Key implications for adult social care practice:

- Continuity of support from community-based workers (which could pre-date and post-date admission) was found by carers in the study to be invaluable during the period of detention, including liaison with and communication around the ward. Such continuity would be an asset.
- Community teams could be part of the process around planning on the wards, in the context of forward planning for service users and for carers.
- Social workers are experienced in and well placed to work across boundaries between services and professions and in client advocacy.
- Support for carers falls within social work's professional remit and fits with its holistic perspective, even if not specifically within individual job roles (although local authorities do have statutory duties to carers).
- In summary, social workers are well positioned both to support carers and to promote carers' needs with other professionals, and therefore it would be valuable to consider the role they can play in enabling change in this area as part of effective cross-disciplinary and collaborative working arrangements in local areas.

FURTHER READING / REFERENCES

Please visit the study page on the SSCR website or contact the lead investigator (contact details below).

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