

Carer involvement with drug services: a qualitative study

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Abstract

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Accepted for publication

2 November 2012

Keywords: carer involvement, drug services, problem drug use

Background Empirical research suggests that involving carers brings benefits to families and services. Consequently, drug-related policy and guidance has increasingly encouraged drug services to involve carers at all levels of service provision.

Objective To explore the purpose and scope of carer involvement with adult drug services in North-east Scotland.

Design, Setting and Participants A total of 82 participants (20 informal carers, 43 service providers and 19 policy makers) were purposively selected to take part in a qualitative study. Eight focus groups and 32 interviews were conducted between 2007 and 2008.

Findings Three themes were identified through thematic coding: ‘Current levels of involvement’, ‘Use of the term carer’ and ‘Opportunities for change?’ Carer involvement was described as limited, unplanned and unstructured, and consisted largely of information and advice, practical and emotional support, and signposting of services. Although use of the term ‘carer’ was contested within and across the groups, caring in a drug context was considered the ‘same but different’ from caring in other contexts. Carers remained sceptical that services actually wanted to involve them in supporting their relative or to offer carers support in their own right. Many service providers and policy makers regarded carer involvement as an aspiration.

Conclusion Encouraging carers, service providers and policy makers to reach a shared understanding of caring in a drug context may help translation of policy into practice. However, there is also a fundamental need for drug services to widen the level and type of involvement activities on offer to carers.

Introduction

Over the past 30 years, carer involvement has gradually become an established part of health

and social care policy in many countries. It is advanced as a means of developing quality and effectiveness of services and enhancing transparency and accountability amongst the service

providers.¹⁻⁴ The potential benefits for service users of involving carers in their treatment include: Improved treatment outcomes, practical and emotional support and having someone to advocate on their behalf.⁵ It is also endorsed as beneficial for carers in terms of enhancing self-confidence, exchange of information and opportunities to learn new skills; and for service providers in terms of promoting job satisfaction, informed decision-making and development of knowledge and skills.⁶⁻¹⁰ Moreover, carer involvement may be regarded as intrinsically worthwhile because of moral imperatives about including people in choices that affect their lives.

Background

There is a long history of research which suggests that involving carers in drug services can bring benefits to drug users and their families. Empirical studies have indicated that interventions that involve families and carers are important in terms of engaging and retaining drug users in treatment; improving drug-related outcomes and family functioning; and reducing the negative health impact on family members.¹¹ Consequently, globally drug-related policy and guidance documents encourage drug services to involve families and carers at all levels of service provision.¹²⁻¹⁷ This has been supplemented in the UK by a general shift towards partnership-working and shared decision-making between service providers and carers, with statutory changes enacted to try to ensure that carers receive equitable access to services and are made aware of their possible entitlement to a carer assessment.^{18,19}

Theoretical models of involvement distinguish between consumerist and democratization approaches.²⁰⁻²² In general, consumerist approaches are based on a market model in which supply (in this case provided by drug services) is influenced by demand (in this case from carers); democratization approaches are based on changing the power dynamic of therapeutic relationships (in this case between service providers and carers). The essential

difference between these approaches is that consumerist approaches do not require service providers to change their underpinning philosophy of care, whereas democratization approaches seek to challenge the existing models of care. The matrix presented in Table 1 outlines a broad range of ways in which carers could potentially be involved with drug services.^{20,21}

Our interest in caring within a drug context stemmed from review work undertaken for the Scottish Executive (now the Scottish Government) which highlighted the key role that families have in supporting drug-using young people through treatment.²³ From our perspective, there seemed to be a certain irony in that, for young people, drug services put considerable effort and resource into involving parents in prevention and intervention, but once the child reached the age of 16 years, this emphasis on working with parents and other informal carers appeared to dissipate.

Research has highlighted a sharp and often antagonistic divide between carers and adult drug services.²⁴⁻²⁸ In particular, carers have complained about service providers not listening when they try to share information and about service providers' reluctance to involve carers in key decisions about treatment. Service providers' or policy makers' perspectives in relation to carer involvement with drug services appear to have been less actively sought by researchers. There is, therefore, a need to gain further insight into how carers, service providers and policy makers view the purpose and scope of their involvement with each other.

Study design

This comparative study used qualitative methods (focus groups and interviews) to explore carer involvement with drug services from the perspectives of carers, service providers and policy makers. Within this study, 'carer' referred to a person aged 18 years or over who identified her/himself as having primary responsibility for the welfare of a problem drug user, in terms of general wellbeing, safety and

Table 1 Levels and types of carer involvement

Types of carer involvement		Democratization approaches	
Levels of carer involvement	Information/Explanation	Consultation	Partnership
Involving carers in support for problem drug users	Treatment plans Telephone help lines	Care planning Complaints/complements procedures Feedback via comment books, suggestion boxes	Family group conferencing Carer interest groups
Involving carers to offer them support in their own right	Information delivered via face-to-face sessions Newsletters from NHS Trust/national organisation/local services Service-led web-based resources, including pod casts, information leaflets Telephone help lines Awareness raising events Dissemination events	Service-led support groups Service-led web-based discussion boards Carer satisfaction surveys	Jointly-led family support groups 1 : 1 counselling ‘Keeping well’ plans Joint development of literature for carers
Involving carers in planning services and developing policy		Conference workshops Expert panel membership	Committee membership Working groups
			Buddying schemes Advocacy schemes
			Carer-led newsletters Carer-led family support groups
			Activist group membership Employment of carers

Adapted from Peck *et al.*²¹ and Hickey and Kipping.²²

companionship. Drug services were defined as community-based services provided by statutory and third sector organizations for those affected by problem drug use.

Setting

The present study was set in a region which has one of the highest numbers of drug users in Scotland.²⁹ Problem drug users in the region mainly use heroin, often combined with other drugs and alcohol. Based on the recent estimates, around 14 000 family members in the region are negatively affected by problem drug use.^{29,30}

Recruitment

Having three groups of participants offered unique opportunities to compare and contrast carers', service providers' and policy makers' perspectives. Having obtained ethics approval for the study, carers were recruited via drug services, advertising in local community centres and snowball sampling. Service providers and policy makers from statutory and/or third sector organizations were identified via publicly available lists of services and recruited through direct contact, in person or by telephone, by one of the researchers (Linda Orr). Purposive sampling was used to ensure diversity in the samples – carers varied in age, gender, relationship to drug user and duration of caring and service providers and policy makers varied in professional training, experience and employing organization. Informed consent was obtained from all participants prior to participation. Recruitment and data generation took place between August 2007 and June 2008.

Participants

The details of the samples obtained are presented in Table 2. All of the carers were related to the person for whom they cared: 18 were parents; one was an aunt and one was sister/daughter; all were Caucasian ($n = 20$). Carers reported taking on caring roles primarily because of someone

else's uncontrolled heroin use and described a wide variety of living arrangements. The service providers ($n = 43$) worked for various community-based services providing health and social care to adults affected by problem drug use; all were Caucasian. Policy makers ($n = 19$) held local, regional or national posts related to the development, organization and delivery of drug services for the population of the region. Five policy makers, all taking part in the same focus group, were also service providers working in local drug services. Only three service providers and two policy makers had specific remits to work with families and carers. Pseudonyms have been used for all participants and for other people who were mentioned by the participants during the focus groups and interviews.

Data generation

Focus groups are a potentially useful means of exploring in-depth experiences and perspectives around specific topics, and for providing an understanding of how misunderstandings or difficulties in communication arise.³¹ However, focus groups might not always be appropriate for those based in geographically isolated locations and not everyone feels able to take part in group discussions. Therefore, individual interviews were also an option – see Table 3. To enhance the potential for comparison, the topic guide was adapted for use with all three groups to guide and encourage discussions around the purpose and scope of carer involvement, how contacts were made and maintained and in what circumstances.

Data analysis

Data analysis involved thematic coding and focused on identifying patterns and seeking to develop an explanatory framework.^{32–34} Separate coding frames were developed for focus groups and interviews, but there was considerable overlap of themes. Coding of transcripts, sorting and collating data, and data retrieval were facilitated by the use of the software package N-Vivo.³⁵ Linda Orr undertook initial and

Table 2 Participants' characteristics

	Carers (n = 20)	Service providers (n = 43)	Policy makers (n = 19)
Gender			
Male	1	17	8
Female	19	26	11
Age			
<30 years	0	4	0
30–39 years	2	11	3
40–49 years	8	23	15
50–59 years	6	5	1
>60 years	4	0	0
Location			
Rural	8	10	3
Urban	12	33	16
Employing organization			
Health care	3	12	6
Social care	3	18	2
Third sector	0	13	11
Other	14	0	0
Job title			
Managers	1	14	11
Workers	3	27	8
Students	2	2	0
Other	14	0	0
Experience of caring/working in drug context			
≤ 1 year	4	12	4
2–5 years	6	21	10
6–9 years	3	8	4
≥ 10 years	7	2	1

Table 3 Numbers of focus groups and individual interviews

	Focus groups	Individual interviews	Total number of participants
Carers	1	14	20
Service providers	6	6	43
Policy makers	1	12	19

subsequent coding of transcripts; Rosaline Barbour and Lawrie Elliott were involved in reviewing the coding frame; and all three contributors were involved in developing the analysis.

Findings

This paper focuses on three overarching themes represented in the data: 'Current levels of

involvement', 'Use of the term carer' and 'Opportunities for change'.

Current levels of involvement

When initially asked about involvement with drug services, most carers described their experiences as 'managing as best we can' without involvement of services. Carers attempted to validate their experiences by emphasizing that they knew other carers who felt the same way. Likewise, most service providers and policy makers initially stated they had limited or no involvement with carers, justifying this with reference to drug users having limited contact with their families. However, as the focus groups and interviews progressed, participants from all the three groups went on to describe limited, unplanned and unstructured involvement with each other.

Support for drug users

Most carers expected services to involve them when their drug user entered treatment and were surprised when this did not happen or happened in a very limited way; involvement was portrayed as intermittent and very much constrained by issues of confidentiality. Most carers stated that opportunistic meetings with service providers within the family home happened infrequently; carers' perceptions were that service providers preferred to meet drug users in service settings. Carers also reported that they were rarely invited to planned meetings with service providers but, when this occurred, these meetings were dominated by service providers' agendas, leaving carers feeling disempowered and undervalued:

Sarah: I mean at the end of the day their job is to help Graeme [her son] and to get him to remain drug-free. The only difference between us and them is they're being paid to do it. So I can't see why... if we all want the same for Graeme, why do they put up barriers and things in the way? (Interviewee, works in health care, son on methadone, carer for six years).

Sometimes carers disengaged themselves with drug services because their own needs, or those

of drug users', were not being met, but more often, carers were coping alone because they felt that they had no choice. A few carers described more positive involvement with services; this appeared to hinge on service providers showing compassion and respect towards the drug user, making efforts to listen to the carer, and providing advice and support in a practical and timely fashion. Nonetheless, at times, carers appeared to question whether all carers could or should get involved with services. For example, Ruth contrasts her own attitude with that of 'other' carers:

Ruth: I'm able to tell Bert [nurse at drug treatment service] exactly what is going on because I'm so involved in looking after Tony [her son]. Some parents who aren't involved and don't give a monkey's about what's going on, well, they wouldn't even go to the drug service with them in the first place, but then... they're maybe in the same situation themselves (Interviewee, works in social care, son on methadone, carer for five years).

None of the service providers reported routinely collecting data about carers' contacts with services (in terms of who attended services, how often, and what actions were taken) nor did they describe utilization of family-focused interventions such as those advocated by the UK Alcohol, Drugs and the Family Research Group.³⁶ Although a few service providers identified home visits as potentially useful in terms of gleaning information about drug users' social circumstances, planned contacts (such as family mediation or case conferences) were rare.

Service providers reported that contacts with carers – by telephone or less commonly in person – were almost always triggered by carers. Although service providers appreciated that requests to discuss drug users' attendance at clinic appointments or progress with treatment were often made by carers in response to perceived crises, such contacts were described as problematic:

Mike: It's difficult because there's a lot of dishonesty. We'll know the true story but the family will have a very different story about the person's drug use and it does put you in a very difficult

position [some mumbling around the room in agreement]. Quite often once you explain that you can't lie for them, they'll be, 'Oh well I don't want you to involve my family then because I've told them a bagful of lies' (Focus group participant, Team Leader, third sector organization, experienced nurse).

Drawing on past clinical experiences, local policy maker-cum-service providers – and several policy makers in regional or national posts – took a similar view of the challenges of involving carers in supporting drug users. Perhaps unsurprisingly, service providers and policy makers who had a specific remit to work with families and carers, who were also carers, or who had additional training in family work emphasized the need for services to make more of an effort to involve carers.

Support for carers

Nearly all of the carers reported being passed from one service to another with no-one seeming to be willing or able to pick up requests for information or support. Such criticisms were most common in relation to primary health-care teams and drug treatment services. Disappointed by the response of local services, a number of carers (almost all of whom worked in health or social care posts) had taken the initiative to contact national organizations that offered advice and support to families affected by drugs.

Only five carers reported to have benefited from securing regular support for themselves from local services – one from a generic NHS counselling service, two from social work teams and two from third sector organizations. Two of these carers worked in health and social care and the other three all had ongoing health issues. These carers had often chosen to meet in anonymous locations (e.g., generic clinic or café) or at home rather than in service settings. A further five carers reported receiving sporadic support from social work services or third sector organizations, but were divided as to whether they considered this helpful:

Sarah: To them [social work team], I'm just a nosey old busybody trying to cause trouble and

interfere. I see it as a parent who is trying to be responsible in getting their son to take on his responsibilities (Interviewee, works in health care, son on methadone, carer for six years).

Most service providers reported providing some limited support to carers in their own right, either opportunistically or in response to crises. For example, the two general practitioners taking part in the study described a typical scenario as one where the carer attended a consultation about their own health issues but ended up sharing concerns about the drug user and the impact of problem drug use on family life. Those working in drug treatment services expressed concerns about sometimes being drawn into supporting carers by default, particularly when the drug users' dependent children were being looked after by extended family members; they suggested that separate services were a better way of ensuring that these carers received appropriate support:

Matt: Just... meeting the carers is difficult in itself... and when you do there's lots of barriers to be broken down, a lot of education to do, which I suppose detracts from what you're actually doing with the patient, and which draws on your resources and moves you off maybe in another direction for a while so... you're probably a bit reluctant to get too deep into that (Focus group participant, Staff Nurse, NHS drug treatment service).

Although the availability of drop-in services for carers was limited in the region, service providers identified them as valuable in terms of allowing carers to access support when they felt ready to talk. Occasionally, the carers' contacts with social work services led to more regular support (sometimes the drug user was already being seen by the service but not always). However, this often appeared to consist of loose arrangements, with no clear plan of care, no agreement about outcomes and no evaluation of whether outcomes had been achieved:

John: I think part of the difficulty is that people are working in services where their primary idea of involving carers is in order to help the client or patient. So the carer isn't actually a patient in their own right in the eyes of the service... unless, of

course, they're on the phone going nuts and complaining... demanding services! They're the ones that end up getting a carer assessment... I don't want to be too cynical about it but that's largely how it is (Interviewee, Team Leader, social work team, experienced social worker).

Policy makers working at national and regional levels emphasized the importance of carer-focused policies, however, those working locally, like service providers, described limited and often reactive contacts with carers.

Involvement in planning services and developing policy

Most carers appeared to have given little consideration to getting involved in planning services and developing policy. When asked directly whether this was of interest to them, some carers were quite adamant that they were ill-equipped for this level of involvement; others, particularly those involved in family support groups, appeared more open to the idea. However, most service providers and some policy makers reported that efforts to involve carers in planning services and developing policy were limited, and believed that there was still a long way to go before carer involvement at this level could transcend rhetoric:

Katie: I think there's a strategic drive which doesn't filter down to grassroots (Charge Nurse).

Violet: It looks good in glossy policy documents! (Senior Staff Nurse)

Katie: You'll get the occasional vociferous and often atypical parent who'll become politically involved because of their own experiences of a son or daughter with drug use problems [rest of group agreeing]... I've known parents take on that role but they'll often campaign from a very personal viewpoint (Focus group participants, NHS drug treatment service).

In contrast, four experienced policy makers (all working at the regional or national level) seemed more convinced that efforts to involve carers in working groups were beginning to have an impact on practice and policy developments:

Pam: Carers are a challenging group but they're also a very willing group when you get them together. *I think* [participant's emphasis] that we, as professionals tend to come in and think we know best so we make engaging carers difficult and actually it's pretty straightforward (Interviewee, Regional Manager, third sector organization, proponent of user and carer involvement).

Use of term 'carer'

The use of term 'carer' was discussed spontaneously and at length in almost all of the focus groups and interviews. When asked whether they considered themselves to be 'carers', around half of the carers answered with conviction that they were. Those who identified with this label were the individuals who had provided physical and emotional support to their drug-using relative for many years and/or were heavily involved in caring for their dependent children. Most of them felt obliged, even pressured, to take on caring roles by the drug user, service providers or both. Despite their array of caring responsibilities, some carers (all of whom cared for drug users' children) claimed that service providers did not view them as carers. For example, Diane (Interviewee, carer for two grandchildren) asserted, 'We want to be recognized [as carers] but we're not getting the chance'.

Eight carers, however, did not define themselves as 'carers', choosing instead to construct themselves as parents 'just doing what families do for each other'. In contrast to the self-identified 'carers' with their long experiences of caring, two had relatively short experiences of caring (Lindsay, interviewee, cared for son for around 12 months before he died; Olive, interviewee, cared for her daughter for 6 months). And the rest were all part of a newly-formed carer-led support group and were caring for drug-using adult children who had no offspring.

The remaining four carers (all mothers) initially ascribed caring to their role as parents and rejected the notion of being a 'carer'. As they described the types of support that they provided to their drug-using children, these carers

drew analogies between caring in a drug context and the physical and emotional demands of other caring situations and, as they articulated their views in interviews and focus groups, began to embrace their 'carer' status:

Nancy: If you were to interview my son he would probably say that the agencies that are there to help and support are fine for talking to about things and making plans... for saying, 'You'll do this and you'll do that', but when it actually comes to the practical help and support its really down to me. And I'm not blowing my trumpet here that is a fact of life (Interviewee, works in drug-related social care, son on methadone, carer for fifteen years).

None of the carers reported having been offered a carer assessment. Indeed, very few of them appeared to have knowledge of such a procedure and, even when it was described, most immediately discounted its applicability to their own caring situation. Those that cared for dependent grandchildren, however, were keen to ascertain whether this might be a means of securing regular financial support.

Service providers and local policy maker-cum-service providers claimed that transgenerational and concordant drug use meant that it was often unlikely that any one person within a family could be identified as a 'carer'. A few service providers further rationalized that having someone identified as 'carer' might be potentially disadvantageous, perhaps allowing drug users to shirk their responsibilities and become even more dependent. A number of alternative terms were suggested, including: 'supporter', 'concerned family member', 'guardian' and 'significant other'. This service provider, a general practitioner, appeared sceptical about the use of other terms and grudgingly accepted that 'carer' might be the best option:

James: 'Carers' is fashionable, it's flavour of the month, it's moved up the political agenda so it's used a lot and... arguably, by giving a certain status to someone involved in care, I think that's advantageous. I think it recognises the role that people play and I think it lets them see that they're not alone (Interviewee, experienced General Practitioner).

Policy makers working at regional and national levels appeared more accepting of 'carer', highlighting its widespread use in policy documents. There was, however, a general agreement among service providers and policy makers that the term 'carer' was appropriate in palliative care contexts (where the drug user was severely debilitated by infectious diseases such as hepatitis or human immunodeficiency virus), when carers were caring for drug users' dependent children and when young people were caring for drug-using parents.

None of the service providers or policy makers spontaneously raised the issue of carer assessments. When specifically asked about the utility of such assessments within a drug context, service providers and policy makers from all types of organizations rationalized that carer assessments would usually be inappropriate because of a lack of physical care-giving or because carers would not regard themselves as 'carers'.

Same but different

In comparison with other caring experiences, carers taking part in this study perceived caring for someone affected by problem drug use to be less predictable and more isolating. Several carers, all with experience of caring in contexts other than drug use, stated that caring for problem drug users was very different from caring for relatives with physical illness or disability in terms of the amount of physical and emotional support that was offered by services:

Karen: It's different... looking out for your son or daughter in a drug context to if they had... cerebral palsy...

Jane: Any illness really!

Karen: ... or really bad asthma [lots of agreement from group]. It would almost be easier if they were disabled...

Hester: Yeah! It's definitely looked upon differently.

Karen: ... because if they were, and I'm being serious here [participant's emphasis], A, people

would see visibly what was wrong with them. B, nobody would blame me for it. C, they'd get all the help and support they needed, and then D, I would get all the help and support that I needed (Focus group participants, carer-led family support group).

Service providers and policy makers claimed that, in comparison to other caring contexts, those caring for drug users were typically regarded as less deserving of help and support. Firstly, problem drug use did not involve the same kind of physical caring as debilitating health conditions such as multiple sclerosis or dementia, and was of a more temporal nature. Secondly, drug use in itself was regarded as a choice. The impact on families and carers of drug users' associations with petty theft and more serious crimes were also regarded as distinctive. Issues of confidentiality and consent were regarded as more problematic. Even so, participants from all three groups concluded that caring in a drug context was the 'same but different' from caring in other contexts, citing similarities in the gendered nature of caring responsibilities, the impact of caring on carers' lives and in carers' needs for emotional as well as practical support:

Katie: With other illnesses, people are much more supportive, sympathetic and... (Senior Charge Nurse).

Matt: Yeah, the difference would be... someone might say, 'Oh, you know, you basically perpetuated this habit by giving them money, giving them shelter, so you just helped them have a habit'. Whereas if that person say had a physical illness it would be, 'Oh, poor you, you're so brave...' (Staff Nurse) (Focus group participants, NHS drug treatment service).

Opportunities for change

Nearly all the carers stated that they wanted more support from services, for drug users, other family members and themselves. Although a few carers believed that separate services would afford them better opportunities to share their concerns and frustrations, given

the choice, most carers were strongly in support of service providers working with both drug users and carers within the same service. They claimed that this was the best way of ensuring that carers were able to support drug users and that misunderstandings were avoided between all parties. Carers also argued that family support groups should be an addition rather than an alternative to carer involvement with drug services. Yet, most carers remained sceptical that drug services actually wanted to involve carers in problem drug users' treatment or to support carers in their own right:

Anna: We're treated like dirt because... [long sigh]... they think 'Och, they're just junkie families' and that's actually the attitude a lot of them [service providers] have. It's no nice for carers, honestly it's not. Carers are... just treated like mugs (Interviewee, works in health care, carer for two dependent children of drug-using niece).

One service provider disclosed that he also cared for a drug-using sibling (Kirk, focus group participant, Team Leader, social work team) and two policy makers disclosed that they were parents of drug-using children (Avril, interviewee, Service Manager, third sector service; Brian, interviewee, Service Manager, third sector service). All three participants echoed the scepticism expressed by other carers in relation to drug services being ready to actively involve carers.

Many service providers questioned whether carer involvement was possible or even desirable within some family situations and whether financial investment in carer involvement was likely to be forthcoming from the Government. Those employed specifically to work with carers, and those in more generic roles, however, seemed to recognize the long-term benefits of taking a whole family approach. Most policy makers seemed optimistic that the higher priority being given to carer involvement in policy and guidance documents was already beginning to influence service provision and would continue to do so. Notably, as the focus groups and interviews progressed, some service providers and policy makers, including some who

had initially been reticent about carer involvement, admitted that they had started to reconsider their position in relation to carer involvement:

Jude: Until you came to speak to me about this, carers would be down the list of my priorities which is a bad thing and I'm glad that you're doing this because it makes me put them up to the front again (Interviewee, General Practitioner, specialist training in problem drug use).

Also worthy of note, is that six of the carers taking part in the study worked in health or social care; and a further three carers had held social care posts in the past. Although these carers advocated strongly for services taking a whole family approach, they also recognized the significant challenges that it presented to services and had similar experiences of finding it difficult to secure the much-needed support.

Discussion

From theoretical work relating to models of user and carer involvement, the level and type of involvement that service providers and policy makers are willing to consider may depend on the amount of power and control they are prepared to relinquish.²¹ For example, giving carers information to let them know what to expect when drug users start methadone programmes requires very little in terms of a shift in power and control whereas consulting with carers about how services can work with them more effectively requires relinquishing a bit more power and control. Entering into partnership with carers requires sharing a significant amount of power and control whereas providing training, advice and resources to support carer-led initiatives requires giving over a great deal of power and control to carers.

However, Tritter and McCallum²⁰ argue that such an emphasis on power and control may be unwarranted; they highlight the need to engage users and carers in discussions about what they actually want in terms of involvement and to recognize that their aspirations might change over time. Although service pro-

viders and policy makers may regard carer involvement as chiefly a matter of information sharing and consultation, this may not match with what carers seek to gain from their involvement with services.³⁷ From the carers' perspectives, such mismatches may result in involvement having a tokenistic feel about it and may undermine confidence in the worth of carer involvement.

Furthermore, the assumption that if carers (as 'consumers') are not satisfied with what services are being offered to them, then they can, and will, go elsewhere for help and support may have particular challenges for carers within a drug context.^{21,22} As carers' relationships with services may be inextricably linked to supporting drug users through treatment, carers may feel that they have little choice but to accept the ideology of the service. The limited availability of services to support carers in their own right also means that, if they decide the service is not responding to their needs, the only alternative open to them may be to cope alone.

The Scottish Government has acknowledged that access to support from services often hinges on whether those in caring roles are actually identified as carers.¹⁸ The findings of the present study suggest that carers themselves are sometimes reluctant to be labelled as carers (rationalizing their input as 'just doing what family does'). This is, although, no different to other caring contexts; empirical studies have long since indicated that carers typically only begin to recognize their 'carer' status as the intensity of their caring responsibilities increase.³⁸ However, within a drug context, this shift towards regarding themselves as carers may be more unlikely because of services' reticence about acknowledging their 'carer' status.

Partnership working is a core element of the latest Scottish drug strategy in terms of working with families and carers, and ensuring a wide range of specialist and generic services pull together to fully address the needs of those affected by problem drug use.³⁹ To date, it seems that attempts to get carer involvement on to service providers' agendas via policy and

guidance documents may have relied too heavily on awareness-raising and general directives.^{13–16} Carer involvement is very much limited to *ad hoc* information-giving and advice, piecemeal practical and emotional support and signposting to services. The findings of the present study (and others) suggest that greater clarity is required about who should be taking the lead in terms of different levels and types of carer involvement.^{25,40}

It is anticipated that the aforementioned matrix (Table 1) could be used to open up channels of communication amongst service providers and policy makers, and indeed carers, about the level and type of involvement that may be possible. Service providers and policy makers will need to be clear about who they wish to involve and why, and to find ways of ensuring that carers know who they are expected to represent and the purpose of their involvement.⁴¹ Importantly, if carers, service providers and policy makers have no agreed basis for carer involvement and no agreed outcomes, then it will be very difficult to evidence change and efforts will not be made to sustain involvement activities.²⁰

Conclusion

The lack of shared perspectives about use of term 'carer' and what it means to be a carer within a drug context creates a tendency for drug services to disregard opportunities to work with families and carers. Although services are likely to have the capacity and capability to offer different levels and types of involvement to carers, there is a fundamental need to establish shared understandings between carers, service providers and policy makers about the purpose and scope of involvement. It may be helpful for drug services to work from the premise put forward by participants in this study, that caring within a drug context is the 'same but different' from caring in other contexts. From there, it should be easier to move towards helping individual drug services to identify what levels and types of involvement they feel able to provide to

carers and help carers to foster realistic expectations of services.

Acknowledgements

The authors express their gratitude to the participants who took part in the study.

Funding

This study was supported by the School of Nursing and Midwifery, University of Dundee.

Conflict of interest

None.

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