

Chronic illness self-management: locating the 'self'

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Chronic illness self-management: locating the 'self'

Aim. In this paper, we present the findings of a recent research project in which we explored self-management with older people who were diagnosed with asthma.

Background. Asthma self-management literature has focused on the need for the patient to 'adhere' to prescribed therapies, in particular the taking of medications, monitoring of respiratory function or recognizing and avoiding triggers.

Method. Data were generated during a period of 9 months from three sources; in-depth interviews with 24 older participants, an open-ended questionnaire and two mixed-gender participatory action research groups.

Findings. Based on current literature, our previous research findings which have 'unpacked' what is 'self-management', and data generated in this project, we propose that three asthma management models are in operation: Medical Model of Self-management, Collaborative Model of Self-management and Self-Agency Model of Self-management. Locating the 'self' in self-management means acknowledging that many people living with a chronic condition are already self-determining and their expertise should be acknowledged as such.

Conclusion. Health care professionals can best facilitate people toward self-agency by embracing new understandings of self-management in long-term illness. This process is enhanced when the expertise a person brings to the management of their condition is given the respect it deserves. There needs to be a focus on providing people with the means to grow and learn in a participative relationship that cannot be fully realized with 'off the shelf' self-management solutions.

Keywords: chronic illness, self-management, asthma, older people, community, nursing

Introduction

The purpose of this paper is to explicate our emerging understandings about self-management when people are

living with chronic or long-term illness. Previous research has revealed that common assumptions about the meaning of self-management for people who have chronic illness require re-evaluation (Kralik *et al.* 2004). In this paper, we present

the findings of a research project in which we explored self-management with older people who were diagnosed with asthma. Although this study gained external research funding from a disease-specific funding body (Asthma Innovative Management: AIM), we suggest that the findings may be applicable across chronic conditions.

Literature

There is evidence that self-management programmes have been embraced by health policymakers as one way to decrease health costs by having empowered and healthier 'patients' accessing health services with less frequency (Department of Health 2003). A literature search strategy in Medline and CINAHL using the terms 'self-management, chronic illness' was used to support our current chronic illness research programme and to inform the study reported here. We sought papers about the condition of 'asthma' and 'asthma management' and we also used Internet-based resources.

The rise of the self-management movement is noted in the literature (Lindgren 1996, Clark & Nothwehr 1997, Bailey *et al.* 1999, Barner *et al.* 1999, Lahdensuo 1999, Costello 2000, Adams *et al.* 2001, Lorig 2001, Barlow *et al.* 2002, Kolbe 2002), and a national conference has been sponsored by the Australian Government (Australian Government National Chronic Condition Self-management Conference 2003). However, close analysis of the literature revealed that a medical prescriptive approach to self-management is widespread, emphasizing adherence to directions given by health care professionals. The 'self' in self-management has been ignored, and the person has been objectified as the 'patient'.

Asthma self-management literature is no exception, citing recommendations of ways to encourage patients to adhere to an authoritarian and prescriptive approach. Patients are expected to be compliant to medical management instructions. Compliance has been defined as adherence by the patient to directions given by the prescribing physician, and good compliance has been considered as 80% adherence or greater (Wilkinson *et al.* 2003). Fishwick *et al.* (1997) provided three basic principles for asthma self-management: objective self-assessment of asthma severity with educated interpretation of symptoms and peak flow readings; use and monitoring of inhaled and oral medications for long-term prevention and treatment of exacerbations; and integration of these self-assessment and management issues into written guidelines for patients to follow. These are clearly medical management criteria and have little relevance to the contextual experience of living with asthma on a daily basis.

Asthma self-management literature has focused on the need for patients to 'adhere' to prescribed therapies, in particular

taking medications, monitoring respiratory function or recognizing and avoiding triggers (Bender *et al.* 1997, Osman 1997, Conway 1998, McGann 1999, Trueman 2000, Fish & Lung 2001, Milgrom *et al.* 2002, Wraight *et al.* 2002). Other terms, such as compliance (Cochrane 1996, Watts *et al.* 1997, Leyshon 1999, Spector 2000, Lindberg *et al.* 2001) and concordance (Riekert *et al.* 2003), have been used with similar intent.

A focus in the asthma self-management literature has been the use (and non-use) of an asthma self-management plan (Ruffin *et al.* 1999). This self-management plan has been considered central to the guidelines provided in the Australian Asthma Management Handbook (National Asthma Council 2002). While some evidence has been cited that asthma management plans produce effective clinical outcomes (Gibson *et al.* 2003), a recent Cochrane Review stated that there was no consistent evidence that written plans produced better outcomes (Toelle & Ram 2001). Either way, it appears that the reality of everyday asthma care differs from what guided self-management plans prescribe, with a less than expected uptake (Thoonen & Van Weel 2000). Beilby *et al.* (1997) demonstrated non-use of plans in a South Australian context and less than half (43%) of adults surveyed who had asthma actually had an asthma management plan. Adults most likely to have such a plan were those living with severe asthma and visiting the same doctor on a regular basis. Detailed written plans were not deemed necessary for people with mild asthma symptoms (Fishwick *et al.* 1997).

Little research has been reported on the way in which older people 'self' manage asthma, outside the narrow terrain of medical management, compliance and generic education. Education 'of' people with asthma has been reported as an intervention to ensure compliance (Bone 1996, Brown 2001). Education has been advocated as being important in ensuring 'compliance' with self-management, and has most often been described in terms of delivering a prescribed package of information either to groups or individually (Wilson 1997). Increasingly it has been acknowledged that targeting individual needs may result in positive outcomes, rather than relying solely on generic education (Ward & Reynolds 2000).

Despite a continued emphasis on medical management and insistence on using the term 'patient', there has been an effort to move away from the authoritarian model toward a collaborative model of self-management. The Australian Asthma Management Handbook (National Asthma Council 2002) outlined a six-point asthma *management plan* which included development of an *action plan* as one key step. There is a distinction between an 'action plan' which is intended reactively to guide-specific interventions (e.g. if peak expiratory flow measurements or symptom are X then

increase Y medication), and a 'management plan', which is a proactive attempt to provide education, support, clinical care and monitoring as a partnership between patients and health care professionals.

Collaborative models insist that, when people living with a chronic condition are provided with education, support, clinical care and monitoring in a partnership with health care professionals, self-management is enhanced (Lorig & Holman 1993, Barlow *et al.* 1999, Holman & Lorig 2000). Bodenheimer *et al.* (2002) have argued that self-management is important to living well with chronic illness, because people have an improved chance for a rewarding lifestyle when they are educated about the disease and take part in their own care. Self-management has been reported as enabling people to minimize pain, share in decision-making about treatment, gain a sense of control over their lives (Lorig & Holman 1993, Barlow *et al.* 1999), reduce the frequency of visits to physicians and enjoy better quality of life (Lorig *et al.* 1998, Barlow *et al.* 2000). However, despite the evidence of cost-benefits and improved health outcomes for people who participate in established self-management programmes, they reach only a small number of people with chronic illness (Keysor *et al.* 2001).

The study

Aim

The project reported here responded to the high prevalence of older people living in the community with asthma. We aimed to understand, from the perspective of older men and women, how asthma had impacted on their lives, and to identify the contexts, barriers and issues that were significant for them. In collaboration with the participants, we attempted to explore asthma self-management models.

Participants

Recruitment strategies sought people over the age of 60, who had been medically diagnosed with asthma and were using, or had been prescribed, preventative medications to use on a daily basis. Recruitment proved difficult because older people living with asthma, particularly when asymptomatic, did not place this condition high on their list of ailments that required consideration. Table 1 outlines the recruitment strategies used. It was clear that some strategies yielded a better response rate. Local newspapers, radio interviews and contact with community health workers were the most successful.

Eight men and 16 women with asthma volunteered to participate in the project. Their average age was 76 years; the

Table 1 Recruitment sources

Sources	Contact	Actual
Radio interviews	7	7
Advertisements in local newspapers	7	5
Referrals from asthma educators	9	7
Public asthma awareness sessions	3	3
Royal District Nursing Service 'Driving Force' magazine	1	1
Leaflets from pharmacies	1	1
Total	28	24

youngest person was 60 years and the oldest 92 years old. Based on an assessment carried out by clinical educators specializing in asthma, 17 people had severe asthma, three had moderate asthma, three had mild asthma and one was asymptomatic. Assessments of asthma status made by the clinical educator were based on each person's medication, frequency of medication use and the participant's self-report of asthma severity.

Ethical considerations

Ethics approval was obtained from an institutional ethics committee. An information sheet outlining the study was sent to interested people after their initial contact with researchers. Prior to signing a consent form, participants were assured that they could withdraw from the study at any time, and that anonymity and confidentiality would be protected. Participants' names in this paper are pseudonyms.

Data generation and analysis

Data were generated over 9 months and from three sources: in-depth interviews, an open-ended questionnaire and two participatory action research (PAR) mixed-gender research groups (equalling eight contact hours).

The second author undertook in-depth interviews with the 24 participants and these were informally conducted in participants' homes. Guiding questions were: How has asthma affected your life? Give an example of an incident or episode with asthma that really affected your life, What has changed in your life since you were diagnosed with asthma? What strategies do you employ to manage your asthma? Where and how did you learn about these strategies? Is there anything that would help you in the future to manage your asthma that is not available now? These questions resulted in the development of a story line for each participant. In addition, the shape of the story was influenced by questions of the type 'look, think and act' (Stringer 1999).

'Looking' referred to the exploratory phase, in which participants were asked to tell their stories about living with asthma. 'Thinking' was stimulated when the interviewer asked them to reflect on their story: 'What is happening here?' and 'Why are things as they are?' The 'acting' phase occurred when participants were asked to think about aspects of their asthma self-management that they would like to change or share with others. Most of the one-to-one interviews lasted 1 hour, and all were tape-recorded and transcribed verbatim.

Eighteen participants volunteered to join a PAR group. Family and friends were also invited, and six partners attended. Due to the large number of people participating, two separate groups were convened. We have published details of the PAR methodology previously (Koch & Kralik 2001, Koch *et al.* 2002) and therefore here we will only give an overview of the approach.

During the PAR meetings, the facilitator (first author) gave an overview of the study and assisted with setting 'norms' in collaboration with the group. A document that contained a preliminary analysis of interview data was presented to participants at the first PAR group meeting. Discussion took place around each of the themes and validation of findings was noted. In an effort to extend group discussion, the 'look, think and act' (Stringer 1999) framework was displayed on a slide and this cyclic process explained to participants. The explanation was as follows: 'Let us *look* at what is going on in your life, let us *think* about this (reflect) and then let us consider what can be done to improve things (*act*)'. This cyclic process encouraged participants to investigate their problems and issues systematically, formulate experiential accounts of their situations, and devise plans to deal with the issues identified.

We held two PAR meetings with each of the two groups and the intent was to develop collaboratively a model that would enable self-management of asthma for older people. Participants shared their stories about living with asthma, and were encouraged to engage in discussion and dialogue, develop mutually acceptable accounts that described their experiences, and talk about ways they managed their condition. They were encouraged to talk about their 'self'-management and explore what they could do to improve this, thus leading to individual or group action. PAR meetings were transcribed concurrently by a skilled research coordinator.

At the first PAR meeting with each group, we asked participants to take home a questionnaire with two items: 'What is asthma?' and 'What is self-management?' We received 14 replies and analysis of the questionnaire data followed the procedure outlined below.

The three authors read the transcripts and analysed data collaboratively. We analysed for self-management claims

raised by participants (Guba & Lincoln 1989). The process of analysis was an adaptation of Colaizzi's (1978) framework, and the steps were to:

- 1 *Read the text in order to understand it as a whole.* This took some time and required careful re-reading of the interviewer's notes to provide context to the interview text.
- 2 *Extract significant statements about the phenomenon being studied.* Statements were cut and pasted into a separate document and re-read.
- 3 *Develop clusters within individual interviews.* Statements were arranged according to common themes within the context of each interview.
- 4 *Integrate clusters into a broad description of the phenomenon being studied.* Six key themes provided the context of the issues, barriers and self-management strategies of older people living with asthma.
- 5 *Validation of findings with participant.* The six main themes were presented, with corresponding significant statements, to the PAR group participants for comment and validation.

Analysis of the PAR group data was also concurrent to ensure prompt feedback of issues to participants, thus creating the opportunity to build our (participants' and facilitators') understandings collaboratively. We consider that rigour was enhanced because the actual voices of participants were included in the text (Koch & Harrington 1998) so that readers can assess the authenticity of the voices. The final study report was given to all participants and further validation of findings occurred at a third meeting arranged once the study was completed.

Findings

Analysed data from the interviews, questionnaires and PAR groups were merged to reveal tentative self-management models. When listening and talking with participants, we discovered that there were three models of asthma management in operation: medical model of self-management, collaborative model of self-management and self-agency model of self-management.

Medical model of asthma management

Most participants identified with a medical model of self-management. The epitome of management of asthma for older people appeared to be taking prescribed medications. Closely tied to this was following orders from the doctor. Mostly, people took responsibility for management of their medications. In addition to taking medications, prevention of asthma attacks was linked to identification and avoidance of

triggers. When people were first diagnosed with asthma, they often found themselves in the medical management model. Jane commented:

I feel I've only had it a short while but I have the right doctor and follow through with my medication. I've learnt a lot. We really must do what the doctors and specialists tell [us].

Jane followed the doctor's orders and respected that doctors held authority about her condition. Isabel reported that her 'doctor did all the managing...I have to check my lung capacity. He monitored it very closely...I had to trust him'.

In this model, the doctor rather than the patient managed the disease process; instead the patient learnt to trust medical knowledge and management. Learning to trust was part of slotting into a medical management programme, precisely because the patient was not invited to take part in asthma management. Medical management was something done to patients and people were expected to comply with medical orders. However, older people might have expectations that doctors would tell them what they should do. Even so, they expected that the doctor's authority and trust should be earned through having specific disease knowledge, Linda expected her GP to provide this knowledge:

I had a heavy cold and she [my doctor] asked if I had asthma – I was thinking, 'You should be telling me!' I went onto the preventer and the reliever – it was good since, except when hot and dry or very cold. I consider (myself) lucky to have developed it later.

Julie added, 'Doctors play a more significant role – I think sometimes the doctor doesn't know what he is talking about'. Jim raised another aspect of medical management:

Some doctors do become complacent with you if you see them for too long. If I have arthritis on my record – it doesn't matter what problem I have, it's to do with the arthritis. I couldn't move my foot off the floor and I went to the doctor and he looked at the card and said, 'It's to do with the arthritis'.

Medical expertise was questioned by Jim, and having another chronic illness label meant that asthma did not receive equivalent medical attention.

Medical management sometimes led to a narrow focus, whereas effective management of asthma demanded that the person's life be viewed in context, and not only as a disease-specific response. Frasier made a claim for holistic management of his asthma:

Well, this rather interests me because I have been asthmatic for years. I have a good background of science. I think we need the set up of special clinics that can give a holistic view of people and their medications, dietary habits, dangers of things like preservatives...It

compounds the trouble. I attended a respiratory specialist and he was not interested in anything outside the immediate present. I'm still having problems. He said, 'Carry on', [but] it's not really the answer.

Older people with asthma often found themselves in a medical management model. However, this meant that the doctor's orders were followed and medications were taken as prescribed; otherwise the *patient* might be labelled as non-compliant. Doctors were likely to be trusted if they provided evidence that they had specific disease knowledge and could offer sound medical advice. For health care professionals, self-management was viewed as the patient adopting appropriate practices in relation to their disease. Medical management took a narrow view whereas management of asthma, because of the long-term nature of the illness, deserved to be placed in the context of the person's life. In this model the person was objectified as 'the patient'.

Collaborative model of asthma management

Another tentative model identified by participants was a collaborative one, which used a combination of biomedical and experiential terms to describe asthma. Some merged their biomedical understanding of asthma with the impact this condition had on their lives. When some older people with asthma talked about self-management, they suggested that this involved other people managing their asthma. However, others described management as a joint effort between them and health care professionals (usually general practitioners), or perceived self-management to be their own agency. Involving participants in a participatory process where they could view both the medical and 'self'-aspects of management gave us an opportunity to find out more about the possibility of developing a self-management model that had 'self' as the centre, and in which the person was viewed as 'the client'. Bodenheimer *et al.* (2002) referred to this model as the partnership paradigm.

Joint effort between participants and health care professionals was most likely to be a result of applying the principles of asthma management in designated asthma clinics. Jane commented:

Going to the GP, having access to an asthma management specialist, put me on the right medication. They did try Pulmicort on me. I had a few different things till they got the right combination. I had the lung function test. I used to be bad under the shower...no energy to wash my hair. At the clinic it was suggested that I buy a towel and dressing gown [and] put that on instead of drying yourself. Same with slippers. I wouldn't have known about using the dressing gown instead of a towel.

It was clear from this example that Jane was offered much more than medical advice. We do not deny that medication information is vitally important for asthma management, but participants emphasized that management of asthma was more than drug management. Jane was involved in her care and was in a position to make informed decisions about her management as a result.

When clients were involved in care, Isabel suggested that 'we bring intelligence to that relationship (with the doctor)'. When input from the client was acknowledged as valuable, this might be conducive to self-agency in management. Naomi, when talking about her relationship with her health care providers, said:

I would say that I have got a very good GP, who put me onto a programme that I carry out strictly. I ring my GP if I've had a couple of days/nights being short of breath and go down and see her, and she writes out the change in medications so I know exactly what to do.

Asthma clinics have only recently been a choice for people in Australia, and clients tend to be people who have been newly diagnosed. Collaborative management seems most likely to be a result of involvement with an asthma clinic. These offered much more than straight medical management advice, and collaboration between GP and client was central. When input from the client was acknowledged and valued, facilitation of the client toward self-agency in asthma management may be possible.

Self-agency model of asthma management

Participants spoke about a model that we have designated as self-agency. Most people had identified their own responses to illness, and some were constantly planning their daily routines as a means of creating order in their lives. Developing alternative lifestyle habits appeared to be important for those who had embraced self-management. Taking control of their own lives was crucial for those who claimed to manage the self, as their accounts indicated that helping oneself was an important aspect of living with asthma. Taking action to deal with it was a part of everyday life, and the person became self-determining.

Some participants talked about self-management solely in terms of their own agency. Others ignored biomedical language and focused entirely on the impact of the condition on their lives and their responses to the impact. Penny described how she had learned to be 'cagey' or 'sneaky' in managing herself, and talked:

...about having osteoporosis and asthma and being on medications for both. It's a vicious circle. I've learnt to be cagey. If I can't breathe,

I go and look at why I can't breathe. If I feel I can't breathe, I might take a Throatie [a soothing cough sweet]. Sometimes that settles it, and I don't go for the big guns first. If at night and it's cold, I put my head under the bedclothes and breathe warm air. You get to be pretty sneaky.

Taking control was evident in stories from people who were experts in management of the self, as Finlay described:

I was on Pulmicort as a preventative. And I put myself off them – told him (GP) I couldn't handle the throat problem. I seem to be able to manage at present. I've done well, considering I'm 87 in a couple of week's time. I do very well and rely on Ventolin largely. I think you should stick pretty close to your doctor and make a note, mentally at least, of things he needs to know.

Finlay had made decisions about which medications he would take, he prided himself on managing the 'self', and he was constantly working out ways to improve the ways he lived with asthma. He made decisions about what to share with the doctor and, in taking control, he had governed his illness. Adams *et al.* (2001) showed that participants wished to remain in control by choosing when to seek care, and wanted to share decisions about initial changes in medication during moderate asthma exacerbations.

Experts in management of the self often have a long learning history, especially when they have lived with the condition for most of their lives (Kennedy 2003). Participants' observations of the changes that had taken place in asthma management during the last 50 years was indeed interesting. We heard about dietary requirements, when a child with asthma was expected to take only 'black rye bread, lettuce and water'. Penny explained that as a 7-year-old child:

I used to have asthma powder...you remember the tobacco tins the men used to smoke? Used to have to put it in a tin and burn it and inhale the smoke. Just makes you want to throw up thinking about it.

Penny's sister, Diane, who also attended the PAR group meetings, said:

When growing up with my sister I was advised to get her out of bed and kneel on her chest and squeeze every bit out of her lungs until she took her breath. Like a resuscitation.

These people were experts on their own conditions and responses to illness because their life experiences had informed them about managing the self. Changes in medical management were monitored with vigilance. These people have seen many asthma management changes, and keeping informed meant that they would be the first to know about better and new ways of managing their condition. In addition

to searching for new information herself, Penny worked alongside her doctor: 'My doctor tells me, 'This is new on the market, so try this'. Penny had undertaken a process of learning from herself, others, peers, and doctors so that she could find a way for asthma to be part of her life. While she was the first to say, 'Asthma can make your life terrible', she concentrated on things she could do – 'write stories, paint instead of playing sport'. She had learned to do things without asking, 'Why me?'

Management of the 'self' was a full-time job. Finlay asked the group to reflect on their self-management:

Are we taking management of asthma for granted just because we have this thing? We have found out for ourselves what is happening, we see articles on asthma, and we ask our doctor who may be more prominent in thinking and diagnosis. I wonder whether we encourage people enough to find out things for themselves?

He had obviously made decisions for himself, and wanted to encourage others in the PAR group to take responsibility for themselves.

In summary, self-management was about reclaiming the self and regaining full human identity. This meant achieving recognition and support for self-monitoring practices.

Discussion

We have articulated three tentative models based on the data generated with participants. Although self-management was shown to have multiple meanings, the dominant model was medical self-management. In addition, much of the literature assumes that self-management means the same to all people – both professionals and those living with a chronic condition. The role of the 'self' was excluded from these discourses; instead, the focus was on medication compliance. However, sometimes alternative or 'softer' terms such as adherence and concordance have been used.

In this study it was identified that the major constraint on self-management was a narrow conception as solely medical management, and notions of patients' self-agency were dismissed. Yet participants who had asthma since childhood were experts in their own self-management, although they were not always acknowledged as such. They were conversant with medical asthma management in the first instance, and subsequently managed the 'self' in the context of their lives. They had developed a sense of mastery (Kralik 2002). Here the term 'self-management' makes reference to the activities these people have undertaken to create order, discipline and control in their lives (Kralik *et al.* 2003).

Whilst we have identified three models of asthma management, we are not to first to use the term 'model' to describe

self-management. The first two models have been previously articulated by Bodenheimer *et al.* (2002); however, the self-agency model of self-management is our theoretical contribution. Older people who had lived with asthma for most of their lives were clearly experts in the management of their condition. Experts in management of the self often have a long learning history, especially when they have lived with this condition most of their lives. Those older people in our study who were at an expert level of 'self'-management were able to conceptualize and use these influences in ways that enhanced their health. With this awareness, they manipulated the extended and external environment to suit their current situation. Changes in medical management supported by research were monitored with vigilance. Those who had had asthma since childhood had seen many management changes, and keeping informed meant that they would be the first to know about better ways to manage their condition. They recognized that asthma fluctuated as life and the illness combined to present new challenges.

When medical help was sought, participants preferred this assistance in collaboration with health care professionals. This was congruent with the collaborative model of care identified by Bodenheimer *et al.* (2002). What made the interaction different was that it was *their* decision to enter this model when acute events occurred or other medical treatment was sought, rather than a health professional benevolently deciding that this was the best course to steer. Taking control of their own lives was crucial in managing the self. Helping oneself was an important aspect of living with asthma, and taking action to deal with the condition was a part of everyday life. Even for these self-determining experts, management of the 'self' was seen as a full-time job.

Conclusion

This study gives a foundation for nurses to understand how older people living with asthma are able to achieve a level of self-agency that does not rely on health care professionals taking the lead role in management. It also highlights that this chronic disease does not just exist in a clinical framework of expiratory peak flow measurement and medication management. Nor does it necessarily require us to provide 'off the shelf' self-management education about how we think that people ought to cope. When nurses cross therapeutic paths with people who have achieved self-agency in asthma management, we must accept that they are the experts and have chosen to use our knowledge and skills to augment their own.

For older people who are not yet self-agents in their care, providing the clinical and social environments for them to

What is already known about this topic

- A medical prescriptive approach to self-management is widespread, emphasizing adherence to directions provided by health care professionals.
- Collaborative models of self-management propose that a partnership exists between those living with chronic illness and health care professionals.

What this paper adds

- Three models of asthma self-management: medical, collaborative and self-agency.
- The self-agency model, advocating self-determination, is a theoretical contribution to self-management discussions.
- An argument for locating the 'self' in self-management.

grow and learn is essential. The way to do this is not to assume we know what they want to learn, but rather to offer a participative partnership that facilitates their control of 'what' and how it is offered.

How can health care professionals provide facilitate self-agency when people are learning to undertake self-management activities? We conclude that both aspects – medical management and management of the self – need to given scope and platform, and offered concurrently.

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