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Exploring the role of companions in learning disability primary care consultations

BACKGROUND

People with a learning disability are commonly supported during their primary healthcare consultations by another person. This may be a family member, or it may be paid care / support staff from a residential care home or other supporting living arrangement.

This support person is crucial in enabling the person with learning disabilities to get the most from a healthcare consultation. This is especially important given the health inequalities people with learning disabilities face. To date, there is scant research on what is required in this role, what good practice looks like, and what the barriers to providing good support may be.

KEY FINDINGS

- Companions are essential in supporting healthcare consultations for individuals with learning disabilities but face challenges due to inadequate training and guidance on their complex role
- Effective support begins before the consultation, including discussions about appointment purpose, patient roles, and required documents. A pre-consultation checklist could help patients and companions prepare and reduce anxiety.
- GPs play a key role in creating a welcoming atmosphere, while mismatched structures between health and social care services can hinder access and participation for patients with learning disabilities.
- Companions navigate a delicate balance between supporting patient autonomy and unintentionally influencing decisions. More guidance and support are needed to enhance their role.

AIMS AND METHODS

This study focuses on the role companions play in supporting patients with learning disabilities when they go to a primary care consultation. This is an important role because people with learning disabilities have health inequalities relative to the general population.

Good support by friends, relatives or staff is crucial for the patient to get the best healthcare possible, and to address small health problems before they become bigger ones that could be more serious with time. The overall aim was to explore the role of companions; to find out what facilitated and impeded successful healthcare communication and experience; and to provide guidance and tips based on expertise by experience and examination of what really happens in practice. The research team did this by:

1) Finding all the relevant writing and research that had been done about the role companions play in supporting patients in primary care in the UK.

2) Interviewing GPs, people with learning disabilities, social care staff, family members and care managers about their opinions and experiences of what good support looks like in practice, and what kinds of things can prevent the patient getting the best support.

3) We filmed 17 consultations for patients with learning disabilities to look closely at how they were supported, what supported patients to remain the focus of the consultation, and what interactional barriers all parties faced.

FINDINGS

Interview/focus group study

Research questions

1. What do key stakeholders perceive to be 'good support' for people with learning disabilities in primary care consultations?

2. What are the perceived barriers to giving or receiving 'good support' for patients with learning disabilities in primary care consultations?

Participants

42 participants took part in focus groups. This included: 22 people with learning disabilities, 7 paid cares, 5 unpaid carers, and 8 social care service providers. Seven GPs took part in interviews. Participants were recruited from across the UK. All participants with learning disabilities had capacity to consent to take part. The focus groups and interviews took place in person and online, depending on the preference of the participants. The data was analysed using thematic analysis.

Theme 1: Support needed before the consultation

Subtheme 1: Preparing for the consultation

GPs were concerned that some paid support workers were not prepared for the appointment and lacked relevant information about the patient. Many GPs

said this was due to the use of agency staff who do not know the patient well, or staff shortages. Some paid carers had systems in place to prepare for the possibility of accompanying someone at the last minute (e.g., due to staff shortage/illness), such as keeping accessible patient records (symptoms, dates, medication and the reason for the appointment) on an iPad or phone that could be accessed by anyone on the team who would accompany the patient. Most participants felt that planning ahead, having conversations about the reason for seeing the doctor and discussing what companions and patients were happy to do in the consultation improved healthcare experience.

Subtheme 2: The impact of the waiting room

Companions and patients reported that the potential for a successful consultation can be compromised even before the patient walks into the consultation room. Often patients with learning disabilities may like a quieter space to wait before the consultation but there are not many options for this to happen. Companions reported dreading long waiting times, and the negative impact this could have on the person they support. This both increased anxiety for patients and companions. Companions reported attempting to ameliorate this by bringing distractions such as headphones, books, cuddly toys, etc. Companions felt that GPs don't understand how booking in and waiting room processes can affect patients with learning disabilities.

Theme 2: Communication and relational support

Subtheme 1: Difficult or delicate conversations

GPs reported the need for delicate approaches in conversations on patient's health and lifestyle. This was both because of how this would be received by the patient, and because of the potential for companions to take suggestions of behaviour change (diet, exercise, etc) as implicit criticisms of the support they provided. Additionally, suggested changes could be difficult for companions because of what was feasible and possible due to factors such as staff numbers/turnover, other responsibilities, etc. Companions reported difficulties weighing up supporting patient autonomy and independence by not correcting inaccurate information given by patients, or to correct/add information to improve health outcomes but risk undermining the patient. Companions and patients felt that GPs often communicated through the companion. GPs felt that companions sometimes talked on behalf of the patient. This led to patient disengagement and negative feelings about attending consultations.

Subtheme 2: Decision making

Some companions reported uncertainty over the extent and boundaries of their role in (supported) decision making. Patients with learning disabilities like to have companions help them make decisions, but do not want companions to take over.

Patients with learning disabilities said companions can play an important role by explaining things in accessible language. GPs reported that decision making that also impacted companions could be difficult to navigate. For example, decreasing mood altering medication will have long-term health benefits for the patients with learning disabilities, but may

be resisted by companions due to the potential for behaviour change and the impact on them and/or the staff team. Companions reported that GPs make or override decisions, GPs feel companions' own agenda can impact the possibility of supported decision making. GPs and people with LD reported instances where companions' personal feelings about patients' healthcare decisions stepped over the line of supported decision making.

Subtheme 3: Qualities & strategies employed by effective companions

- Rephrasing key words or information, checking for understanding and clarifying information during and after the consultation.
- Advocating (with pre-agreement) for the patient, and pushing for more information (especially related to medication changes and side effects).
- Reading verbal and nonverbal cues of the patient to identify when their support was needed or being sought.
- Knowing the person, their wishes and their medical history.
- GPs felt that more support and training was needed to help companions support decision making in line with the Mental Capacity Act.

Subtheme 4: Lack of continuity of care

Patients with learning disabilities and companions expressed frustration that they often did not see the same clinician each time. This makes patients with learning disabilities feel nervous. Some suggested that the new doctor should meet with patients with learning disabilities in the final consultation of the previous doctor. All clinicians said it was not uncommon for patients to be supported by someone who did not know them well (e.g., 'bank' staff). This could render the appointment not worthwhile, and increase clinician workload as well as overburdening the health care services, as GPs (in the best case scenario) had to phone relatives/the home to get missing information and re-book another appointment. With both clinicians and companions being reported to change frequently, the relational and healthcare needs of the patient may get lost.

Theme 3: The misfit between health and social care services

Companions often had to spend lots of time making appointments, using up paid hours on this task. This could negatively impact people with learning disabilities, who may have to decide between using paid support to make/attend appointments, and other key life tasks (shopping, socialising).

GP appointments were scarce and with limited availability. Often, they did not fall in the paid companions' hours. Companions reported often accompanying the patient in their own time rather than miss the appointment or attend alone without support. Concern was expressed that the limited availability of times could mean patients do not get support when they need it.

Conclusions

- Support should be tailored to each patient, for each consultation – this should be done in collaboration with the patient before the consultation.
- There needs to be continuity of care

and support from GPs and companions to reduce health inequalities.

- There is a lack of clarity and guidance for companions, especially around the Mental Capacity Act and their role within it.
- The structures of social care and healthcare often do not align, and people with learning disabilities risk increasing health inequalities due to this misfit.
- There should be further knowledge exchange between patients with learning disabilities, companions and clinicians regarding how best to support patients with LD, what factors can impede successful consultations, and what reasonable adjustments can be made before, during and after the consultation.

Conversation analytic study

17 consultations were recorded from 9 primary care surgeries across the Southwest. The recordings feature 11 primary care clinicians, 17 patients with a range of learning disabilities, and 19 companions (parents, partners and paid support workers). Five companions were paid carers, with the remaining 14 being family or partners. Four data sessions were conducted with co-researchers with learning disabilities to examine the data and focus on their observations.

1: Companions' strategies for supporting patient communication and engagement

The researchers observed companions using a range of strategies to keep patients at the centre of the consultation.

1.1 Tag and polar questions

Tag and polar questions were often used by companions where patients had limited verbal capacity.

Rather than talking about them, companions sought confirmation and additional information from the patient. Take the following example, where a clinician asked the parents of a patient (Liv) with profound learning disabilities for the reason for the appointment. Liv was able to say 'yes' and 'no'.

1 COM1: Um, and recently Liv's skin was not quite so good, was it Liv?

2 PAT: No.

This was common strategy for companions to recruit involvement and participation from their offspring, acknowledging the patient's knowledge whilst detailing symptoms. They also used polar (yes/no) questions to act as intermediaries between clinicians and patient. In the following extract, the GP addresses the father (Com) of a young woman with profound learning disabilities. The father readdresses the question to the patient.

1 DOC: ((Looking at patient's father)) Any problems as far as you're concerned 2 with ears nose and throat?

3 COM: ((looking at the patient)) You alright with your ears nose and throat?

4 PAT: Yeah.

Tag and polar questions to the patient were used by companions even when questions were addressed to them. This prevented the consultations being a dialogue about the patient in their presence.

1.2 Reformulations

Companions routinely reformulated (rephrasing talk from another person) clinicians' talk or questions into accessible language for the patient. Knowing the patient's communicative ability and level enabled them to support patients to answer for themselves. This was often preceded by silence from the patient following a question from the clinician.

1.3 Repairing talk

Sometimes patients with learning disabilities have speech that can be difficult for those who do not know them well to understand. Companions play an important role in repairing talk and maintaining intersubjectivity when clinicians do not understand the patient's utterance. In the following extract, the GP asks Jean (a woman with mild learning disabilities but with difficulty speaking) for the reason for the visit.

2 DOC: Do you want to tell me what's going on and how I can help?

2 PAT: My ( ) hurts

3 DOC: Your (.) knee hurts↑

4 COM: Her leg.

5 DOC: Your leg hurts?

6 PAT: ((Nods))

Here the companion steps in to correct a misunderstanding from the GP. The GP then uses this as an opportunity to check this with the patient, reasserting the patient's right to confirm about her own health.

1.4 Lowering epistemic authority & questions

'Epistemic authority' refers to who treats themselves, or others, as knowing (or having the right to know) about a state of affairs – in this case, the patient's health, symptoms and medical history.

Companions often asked patients questions to confirm which presupposed they did not have full epistemic authority to talk on their behalf ('was it your hip that was hurting?'), even when it became subsequently evident that they knew the answer. This demonstrated companion's awareness of the epistemic rights of the patient in their own consultation. This strategy was also used by companions to elicit additional information from the patient to expand on their answers.

1.5 Giving praise and reassurance

It was far more common for companions rather than clinicians to 'give praise' to patients for complying with the requests of clinicians or for complying with routine checks. Likewise, they supported patients by giving reassurance whilst checks (blood test, blood pressure, etc) were ongoing ('It's okay, try and relax a bit. Think of something nice. There you are, all done').

1.6 Mediating

Companions often mediated between patients and clinicians, providing information and context that may not have been clear from clinician's turns.

In the following extract a dietician (CLI) introduces himself to the patient (Amanda).

CLI: [How]ever we did chat on the phone (.) at some point I think um=

COM1: =>Did we?<= CLI: =last year. Very, very [briefly]. COM1: [>Oh right<], okay.

CLI: And Amanda (.) Hi Amanda!=

COM1: =Amanda this is Jimmy. We're gonna

talk about food. Is that alright?

Here the clinician establishes to the parents of the patient they have not met before, but did talk on the phone. His introduction is mediated by the companion to Amanda; likely because he did not give her his name or the purpose of the visit.

2. Interactional and relational issues

2.1 Adding information

Companions often added additional health information following a question by the clinician and answer by the patient. This serves an important function in ensuring relevant information is given, but could be done in ways that cast the patient's response as insufficient, or in ways that built on the patient's response.

2.2 Compound questions

Clinicians often asked patients with learning disabilities compound questions (two or more questions are combined into one). Take the following example.

1 DOC: How much help d'ya have in terms of getting yourself washed, getting yourself dressed, going to the toilet,

2 PAT: I have a shower.

In this example, the patient answers the first part of the question but not the others. Compound questions often do not work for patients with learning disabilities as they are met with silence or just answering one of the questions, requiring additional work from clinicians and/or companions.

2.3 Companion resistance to clinician proposals

Sometimes clinicians proposed treatment recommendations or lifestyle changes that were resisted by companions (medication reduction, booking a dentist). These were often cast as problematic because of the impact they would have on companions themselves, and their ability to facilitate these changes. This was managed by clinicians through returning to these issues later in the consultation and obtaining uptake by seeking the companion's willingness to try (e.g., 'would you be willing to try doing X'). In general, relatives pursued their own agendas actively rather than resisting reactively, as in the case of paid companions.

2.4 Companions challenging patient's points of view

Companions may have their own objectives going into the consultation which become evident as the consultation progresses. These may differ from the patient's wishes. At times, companions recruited the clinician's talk to add weight to their argument ('see, it's not just me nagging you') which could result in the patient becoming audibly and visibly annoyed. Sometimes companions' own objectives are clear from the start. Take the following example, where Tom (patient) is accompanied by his wife to an annual health check.

3 Doc: From a physical health or mental health perspective are there any concerns your end that you wanted to talk [about]

4 COM: [There] is from my end.

Before the patient has had a chance to answer the clinician, the companion comes in in overlap with the clinician to initiate talk about her own concerns regarding the patient.

2.5 Future decision making

Sometimes clinicians asked patients about making decisions about their health (e.g., medication change). At other points, these decisions were explicitly asked of the companion, even when the patient had capacity to make decisions for themselves ('do you think you want to increase her dose a bit?'). Companions could support patients by reframing the clinician's proposal and checking their acceptance of it.

2.6 Talking about the patient

Pronoun switches by clinicians or companions (from 'you' to 'he/she') often engendered lengthy sequences when patients were talked about and not to. At times this resulted in patients struggling to regain the interactional floor.

2.7 Differences between paid and unpaid companion interactions

It was not possible to outline concrete differences in interactional approach between paid and unpaid companions given only 5 of the 19 companions were paid carers. However, we noticed some marked differences within this limited dataset. In general, paid companions more commonly allowed the patient to answer questions for themselves, even after lengthy silences, rather than stepping in to answer in response to possible interactional trouble.

This could be enabling, letting the patient to answer for themselves (which they often did successfully), but could also leave the patient struggling to provide an answer. Paid companions generally deferred to the patient's knowledge about themselves, even when adding information ('was it your hip that was hurting?'). Unpaid companions (family, partners or spouses) sometimes treated themselves as having primary right to dictate the topic and focus of the consultation ("I wanted to talk to you about his (the patient's) weight"), even with patients who could advocate and speak for themselves. This was not the case with unpaid companions, who generally only entered the interaction in response to a) patient eye gaze selecting them after silence/trouble in answering; b) to clarify or add information the patient had given; or c) in response to a direct question from the GP.

CONCLUSIONS AND IMPLICATIONS

These findings are from a relatively small data set (49 participants in interviews and focus groups), and 17 filmed learning disability primary care consultations (11 primary care clinicians, 17 patients with a range of learning disabilities, and 19 companions. However, they suggest the following:

- Companions play a central role in enacting successful healthcare consultations for people with learning disabilities. However, participants reported a lack of training or guidance for navigating the complexity of their role.
- Successful support begins well before the consultation itself. Discussions regarding the reason for making the appointment, what will happen, what role the patient wants the companion to play, and what documents to take and who wants to hold them (medication lists, health correspondence, etc) can support patients to be actively involved in the consultation and reduce anxiety. This suggests the need for an accessible pre-consultation checklist for companions and patients to work through.

- GPs play a vital role in putting patients at ease. This can be as simple as coming to get them from the waiting room, introducing themselves and outlining the structure of the consultation and what will happen.
- Participants perceived a 'misfit' between health and social care services; the way healthcare appointments and access are structured often did not fit the reality of social care, or the needs of patients with learning disabilities. This can result in consultations being offered on days the patient does not receive social care staff support, leading either to staff attending on their days off, or potentially the person with learning disabilities not going, or going alone.
- Companions play an important role in brokering understanding between clinicians and the patient.
- Companions and GPs can momentarily exclude patients from the consultation by answering on their behalf; speaking about them rather than with them.
- Who the GP asks the first question to can set the participation framework for whether the patient or companion is the interactional centre of the consultation.
- Supporting decision making in practice is difficult for companions, balancing their own feelings, concerns and knowledge about the person with supporting autonomy and choice.
- Companions often walked the line between supporting decision making and inadvertently influencing decision making. There is a lack of guidance and need for increased support for their role under the Mental Capacity Act (2005)

STUDY INFORMATION

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Misfits

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