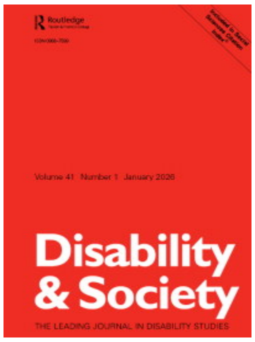

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Rethinking how people with cognitive disability complain

Paul Tomaszewski[a], Karen R. Fisher[a], Sally Robinson[b] and Heikki Ikäheimo[a]

[a]UNSW Sydney, Sydney, Australia; [b]Flinders University, Bedford Park, Australia

ABSTRACT
Policy reforms in Australia aim to facilitate the choice and control of people with cognitive disability about their paid support, yet little is known about how they complain within their support relationships. The study applied recognition theory to data from interviews using creative methods (photos and art) with 11 pairs of people with support and their chosen workers about their reactions when they did not like something. People complained using a variety and combination of words, actions and omissions. Workers often did not notice or interpret people's reactions as complaining. The findings suggest that supporting a person to complain requires approaching the relationship as one of mutual recognition that seeks ways to express a need for change. If support workers and organisations more broadly conceptualised complaining by people with cognitive disability as including reactions when they do not like something, they could be more likely to notice and respond.

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Complain; NDIS; neglect; harm prevention; feedback; human rights

Point of interest

- We looked at how people with cognitive disability complain when they do not like something in their relationship with their paid worker.
- People often needed support from workers to help them understand what they did not like and what they could do about it. But workers often did not notice that people were complaining.
- Some people used words to complain. Some people complained by leaving the room. Other people complained by yelling. Some people complained by staying silent.
- Workers and organisations can improve the way they notice and respond when people complain. One way is to understand complaining as a wide range of reactions to things people do not like.
- Encouraging practices for reflection between the person and worker about complaining could improve the quality of supports in these relationships.

CONTACT Paul Tomaszewski p.tomaszewski@unsw.edu.au.

Introduction

Despite substantial reform to the way disability services in Australia are organised, there has been no end to experiences of everyday indignities by people with cognitive disability in paid support relationships (Fisher et al. 2021; Robinson et al. 2023; Cortis and Van Toorn 2022). People with cognitive disability continue to experience harms at much greater rates than people without disability (CRE-DH. (Centre of Research in Disability and Health) 2021; Cadwallader et al. 2018) and these experiences are often not well noticed or responded to (Thornberry and Olson 2005; Howard et al. 2021). Within the context of market-based and rights orientated reforms toward the way services are designed to promote people's choice and control (Bigby 2020), this problem needs to be addressed as a priority.

Paid support relationships are core within services, intended to protect and promote human rights of people with disability (Cortis and Van Toorn 2022), but very little is known about whether, why and how people complain when they do not like something in the relationships. Rather, people with cognitive disability are considered among the least likely group to complain (Mellors 2014). Because little is known about how people complain, it is unclear whether the conceptualisation of complaining and practices of disability support facilitate the right to complain.

This qualitative study explored how people with cognitive disability complain when they do not like something in their relationships with their paid support worker. The study is concerned with complaining that occurs within the relationship, as distinguished from a complaint or formal grievance. For the purpose of the study, the difference between complaining and complaint can be articulated as: all complaints are complaining, but not all complaining are complaints.

The findings set up a conceptual understanding of complaining by people with cognitive disability. Understanding how people complain might make it easier for workers to notice and respond when people have a problem.

Background

As a concept, complaining has received limited research attention (Kowalski 1996, 2002; Kowalski et al. 2014; Norlock 2018). It is a commonly used term, but its meaning often blends into other common sense concepts, such as blaming and accusing (Taurogiński et al. 2023). The scholarship about complaining usually frames complaining negatively (Kowalski 2002). This negative association of complaining extends to the time of Aristotle and Kant who described the act of complaining as both effeminate and something that should never be done (as cited in Norlock 2018).

Definitions of complaining vary substantially across the literature. The most common type of complaint described is expressions of dissatisfaction by customers aimed at organisations – such as complaining to express dissatisfaction with a product or service (e.g. Min, Lim, and Magnini 2015) using words and formal processes (Simmons and Brennan 2017; Salge et al. 2018). The second type of complaining is about complaining that occurs in social relationships, which are not customer service or product orientated. Scholarship that examines complaining within relationships is sometimes defined as a voiced display of suffering or negative experience where responsibility is sought or attributed to someone (Heinemann and Traverso 2009).

The literature focuses on complaining as a statement, mostly in words (rather than a spectrum of response), intended to communicate dissatisfaction to someone. Complaining is described as an action intended by the complainer to be noticeable by the complainee as an expression of dissatisfaction, whether experienced by the complainer or not (Kowalski 1996).

Research about complaining by people with cognitive disability is scarce. Some scholarship involving people with cognitive disability refers to complaining, although usually not as a central focus of the investigation (e.g. Bigby, Bould, and Beadle-Brown 2017; Topping, Douglas, and Winkler 2023). In other studies, commentary about complaining is supplementary to the overall study (e.g. Fisher et al. 2021; Robinson et al. 2023), or about reporting pathways for people with disability to complain (Wadiwel, Spivakovsky, and Steele 2022; Davy et al. 2025).

The relative scarcity of literature about complaining by people with cognitive disability suggests the need for a more nuanced analysis of complaining. Building on the findings that complaining is an expression of dissatisfaction, this section examines what is known about how people react when they do not like something. The examination of what is known about how people react to what they do not like may help inform how people complain, even where researchers do not refer to the action as complaining.

Words

Literature about complaining by people with cognitive disability often privileges words and focusses on the barriers and enablers for people to make formal complaints. Complaining mostly focusses on whether a person does or does not formally report experiences of abuse perpetrated by workers (e.g. Caspi 2024; Wessel et al. 2012) or other authority (e.g. McGilloway, Smith, and Galvin 2020). The availability of trust relations has been identified as a mediator for whether people use words to express when they are safe (Robinson and Graham, 2019; Robinson and Graham, 2021).

Silence and less noticeable complaining

Research shows that when people with cognitive disability find it difficult to refuse support or want to change plans with their workers, they may do so by using indirect communication, such as refusing to move or staying silent

(Robinson et al. 2023). Domestic violence research, with and without people with cognitive disability, also highlights that people might report experiences of harm in less easily noticeable ways or not at all (Collings et al. 2020; Dew et al. 2019a; McCarthy 2019; Shaheen et al. 2020).

Although not referring to the perspectives of people with cognitive disability, some researchers argue that people's unnoticed reactions to things they do not like are themselves sources of social pain (Vangelisti and Brody 2020). This pain may in turn reduce people's resources to respond in constructive and noticeable ways (Vangelisti and Crumley 1998). Further compounding this experience, are findings that suggest unresolved harms may linger even in the absence of new social threats (Riva, Williams, and Gallucci 2014), which may in turn affect whether people react in noticeable ways.

Behaviours

Literature about people's responses to environments and conditions they do not like often describes the responses of people with cognitive disability as "behaviours" (Cunningham, Macfarlane, and Brodaty 2019; Jorgensen, Nankervis, and Chan 2023). These are described as behavioural responses to conditions that people do not like as protest or resistance (Macaulay 2018; Ramcharan 2009). Much of this scholarship also includes critiques about the use of descriptive language, most notably 'challenging behaviour' (Chan 2016; Markwell 2016). These behavioural responses can be about external and internal conditions, such as a need not met (Cunningham, Macfarlane, and Brodaty 2019; Markwell 2016). The behaviours can include observable, culturally unusual behaviours, which might risk the safety and wellbeing of the person or others (Emerson and Einfeld 2011).

Informal modes

People with cognitive disability often rely on informal modes of communication to express their preferences, such as gestures and facial or verbal expressions (Beukelman and Mirenda 2013; Forster and Iacono 2007). These modes of expression imply the importance of practitioners noticing and responding to the range of ways that people make decisions or communicate need (Williams and Porter 2017). This point is reinforced by scholarship about the way people with cognitive disability communicate pain, contentment and distress using actions and expressions (Cooper 2018; McKenzie, Smith, and Purcell 2013).

Framework for analysing complaining

The focus of this paper is on how people with cognitive disability complain when they do not like something in their relationship with their paid support worker. The analysis is informed by Honneth's recognition theory (Honneth

1995). Recognition theory offers a lens to examine individual and mutual experiences of people and workers (Banks 2018). The theory proffers that social recognition is fundamental to human interactions and supports positive development and maintenance of self-identity (Robinson et al. 2023). Honneth (1995) defines these modes of recognition as: (a) 'love' or care, which enables self-confidence; (b) 'rights', which enables self-respect; and (c) 'solidarity' or social esteem, which enables self-esteem.

According to Honneth, the absence or withdrawal of social recognition becomes an impediment of capacities for self-realisation (Rossiter 2014). Honneth calls these experiences misrecognition. Misrecognitive experiences impact on a person's psyche, and conception of self, or sense of self (Honneth 1995), possibly resulting in people developing a "confining or demeaning or contemptible picture of themselves" (Taylor 1994, 25). Within the modes of recognition, Banks (2018) suggests that misrecognition may be seen, at a love level, as physical or emotional abuse; at a rights level, as constant supervision and institutionalisation; and at an esteeming level, as stigmatisation or humiliation. In practice, the three modes interact (Robinson et al. 2023). The focus on misrecognition provides a nuanced lens to examine subtle and cumulative effects of harm that may prompt complaining and manifest as self-oppression even where obstacles to that advancement fall away (Taylor 1994). This research focusses on how people react when they feel misrecognised in their relationship with their paid worker.

Methods

The data are drawn from a wider project about how relational and institutional conditions affect whether and how people with cognitive disability complain when they do not like something in their relationship with their paid support worker (Tomaszewski 2024). The research used an accessible research approach that aimed to treat people with cognitive disability as research participants rather than respondents (Walmsley 2001). In making the project accessible, one goal for the research was that activities were appropriate, interesting and achievable for research participants. The researcher worked with Research Advisors with cognitive disability who were recruited by the partner organisation. Research Advisors provided guidance on project activities and design. Research Advisors also determined whether the research was important and interesting to them. The research question framing this paper is: How do people with cognitive disability complain when they do not like something in their relationship with their paid support worker?

Research participants

Study participants were recruited using purposive sampling through one organisation that provides a range of disability supports throughout most states in Australia in 2020. Purposive sampling is a non-probability type of sampling which involves identifying research participants who are well suited to answering the research question (Cook and Cook 2017). Given the sensitive research topic, purposive sampling was the most appropriate sampling method for this study as suitable participants require characteristics to address the research question.

An electronic search was conducted to recruit a non-government disability organisation that was accredited against the NDIS Practice Standards and provided supported accommodation or in-home supports to people with cognitive disability. The researcher made contact by email by outlining the broad goal of the research and extending an invitation to a senior manager from the prospective research partner organisation. The invitation was accepted by the first and only senior manager approached. The method, limitations and expectations were then discussed over subsequent meetings with representatives from the organisation and a formal partnership letter was drafted, agreed to and signed by the researcher and the organisation.

The organisational partner identified a key contact person who acted as the primary contact throughout the research. The key contact had no management responsibilities and identified and met with all prospective participants, discussed the research aloud with participants and provided research information and consent forms to interested people with cognitive disability and their chosen worker partners. People who were interested in the study were asked to nominate at least two workers they would like to work with. The purpose of selecting more than one worker was to navigate circumstances where a worker did not want to participate, although this did not happen. The key contact met with prospective workers individually to discuss the research. Interviews were scheduled through the key contact with input from people, workers and the researcher.

The term 'cognitive disability' is used in this paper. Consistent with inclusive methods, people self-identified as a person with cognitive disability (Walmsley et al., 2018). Cognitive disability is often used interchangeably with intellectual disability (PWDA, 2021; Wiesel and Bigby 2015) and in this study included other medical labels (borderline intellectual disability, acquired brain injury, autism and developmental disability) (Douglas and Harpur, 2016).

Dyadic interviews were used for three main reasons in this research. First, the inclusion of a chosen support person as part of dyadic interview promoted choice and self-determination as well as assisting the person to improve their participation in the research (Caldwell 2014). Second, the method allowed exploration of the interdependent support relationship, including observations about how the pair negotiated or supported one another. Third, the involvement of workers and multiple interviews, individually and paired, across different time periods supported triangulation and member checking (McKenzie-Smith, 2020).

The study approach followed the guidelines and ethical procedures approved by the Human Research Ethics Committee at the University of New South Wales (UNSW) prior to fieldwork commencing, with approval number HC210535. Consent was reviewed prior to each interview commencing, and after any question had been satisfactorily answered. The researcher also followed principles of assent, watching closely to assess a person's willingness to continue to participate in the research by observing their verbal and non-verbal cues (Beresford et al., 2004).

A diverse sample of eleven participant pairs were recruited, comprising 6 women and 5 men with cognitive disability and their 10 chosen support workers ranging in age from late teens to early sixties (2 people nominated the same worker). All people received support from their worker where they lived for up to 24 h per day. Five people lived by themselves and six people lived with housemates. Study participants reflected diversity in gender, age, living or support situations, and geographical location. They all communicated using spoken words. Self-identification with the research criteria included being a person with cognitive disability, or worker. To avoid a deficit focus, people did not provide details about their disability for data purposes (Shogren, Luckasson, and Schalock 2018).

Data collection and analysis

The dataset for each pair was interviews conducted at each person's home using social maps and photo elicitation. The creative methods used with people with cognitive disability avoided reliance on spoken communication and stimulated opportunities for broader involvement in the research (Robinson et al. 2023; Banks, 2016; Lutz 2020).

To address the ethical challenges about the complaining topic, the research used the indirect concept of 'change' about where people lived. This topic was a strength and constraint of the project, each described below. The concept of 'home' was chosen as a concrete reference tool for the person with cognitive disability and their support worker, which they were expert in, from which to explore other concepts (Hollomotz 2018), including complaining. Indirect methods were chosen for three main reasons. First, the negative connotations associated with complaining might result in someone not complaining to avoid being seen as complaining, or a complainer. Second, the research presented an ethical risk of harm to the relationship in the pair if they were directly asked about complaining about each other. Third, the paid role of the worker added dimensions of professional responsibility and differences in power (Shakespeare, 2014). These power imbalances might affect whether and what people chose to disclose (Ansello and O'Neill 2010).

The first interviews were semi-structured to develop a social map about the person's experience of their home and the pair's shared understanding of what they did together. In individual interviews immediately afterwards, people and workers reflected on the social map and working together. The social maps supported member checking and were used to assist the pair to complete a photo project to further explore how they worked together, using photovoice methods to elicit data about their relationship (Overmars-Marx, Thomése, and Moonen 2018). In the second round of fieldwork, separate interviews were conducted first, followed by joint interviews. Interviews ranged from 45 to 65 min, and were audio recorded and transcribed with consent. Researcher observations were recorded, including observations about the environment, dynamics and engagement of the participants.

Data were collected about people's experience of misrecognition to highlight the things people did not like in the relationship. The data about how people reacted to experiences of misrecognition were coded based on what people said and showed (what could be observed). Research participants' interview responses were transcribed, coded and organised thematically, and stored using NVivoTM v14 (QSR International). Thematic Analysis (Braun and Clarke, 2006) was conducted using Iterative Categorisation (IC) (Neale 2016) to support accessible and transparent coding. Development of the coding framework for misrecognitive experiences was guided by the modes of recognition and misrecognition (Honneth 1995). The framework for how people reacted to experiences of misrecognition developed during the application of iterative categorisation. This meant the coding framework changed inductively throughout the coding and analytic process (Neale 2016). Visual data was used as a prompt during interviews.

Korstjens and Moser (2018) quality criteria for trustworthiness of qualitative research were used to guide the design and critique of the study. The study used multiple methods with paired and individual member checking, frequent debriefing with supervisors, member checking and presentation at public seminars to critique approach and findings (Richards 2013).

All names in the article are pseudonyms chosen by the participants and the data are anonymised. Some pseudonyms chosen may not reflect the person's stated gender.

Results

Six key modes of complaining were drawn from the data. The ways people reacted to what they did not like were talking to someone they trusted; using verbal or physical force; being silent; changing the way they interact with others, including through body language; and retreating to their room or to a quiet space by themselves. Reacting included what people did or did not say or do. The term ‘react’ is used to denote both the internal response and external expression, whether intended or not, of what they did not like. Importantly, these results should be read in the context of the broader study which identified key interpersonal (such as quality relationships, external support relationships) and institutional themes which affected whether and how people complained (Tomaszewski 2024).

People did not always speak directly about how they reacted when they did not like something. Partly this could be because it was not ethical to ask people to focus on these experiences, or their own or other people’s reactions to them, due to the risk of trauma. Additionally, when they were asked ‘what happens when you disagree with your worker’, people often said disagreements with their workers did not happen or that they did not know what happened when they disagreed. As the findings in this section demonstrate, people’s reactions were sometimes shut down by workers, creating a climate where people might expect speaking about disagreements would not be welcomed. However, some people spoke about things they did not like in their relationship (misrecognition) and said and showed how they reacted to what they did not like.

Talk to someone trusted

Everyone said they would tell a trusted worker when they had a problem and they commonly named between one and three workers. Batman said, ‘[I would talk to my worker] Jane, because she’s a most trusted adult.’ However, the interviews and observations showed that people did not always talk to a trusted worker when they had problems, even when the worker was available and accessible to speak with. They did not often speak with the worker directly and they reacted in other ways more often. Vivienne’s worker, Sal said,

> And so because I was joking, and she couldn’t like tell that I was joking anymore, Vivienne got upset, which caused her to walk out the house and go down the street and stuff. And then I thought we were okay. But after I got home, I received a call from the team leader telling me that Vivienne had complained to her.

Some people said they would react outside the relationship when they had a problem, like Vivienne above. When people reacted outside the relationship, they said they only used words. They said they may talk to a team leader; a family member (albeit fewer than half of the participants said they had contact with their family); or an advisor, such as a counsellor. Of these external support networks, only one person spoke about how their external network helped them to understand the problem, including if, what and how they could do something about it. Rose discussed how her counsellor helped her to make sense of what she did not like. Rose said she helped her find words she could use to describe what she did not like and who she could talk to. Rose said, 'Nah, I sort of bundle it up inside. But I sort of … talk about it. I go to the counsellor for my anxiety and they help me unbundle it. And the words to say.'

More commonly, people said they talked to external networks to better understand whether they could react when they did not like something. This situation arose during an interview with Mario. Mario described his home and spoke about some difficulties that he had with his housemate. He had asked the worker to fix it but the worker did not. Mario asked the researcher whether he thought that what he disliked about his housemate was something he could talk to his support worker about again.

These findings indicate that some people benefited from talking to people outside the relationship to better understand whether, what, how and to whom they might react within or outside their relationship with their worker.

Verbal and physical actions

Sometimes people complained in ways that they intended to communicate dissatisfaction. When they did this, their complaining was often connected closely to the event or condition they did not like. This proximity meant that sometimes people's complaining was more noticeable as an act of agency. Some people were also clear about the outcome that they wanted from this type of complaining.

> Evi: What do you say when workers come into your room while you are sleeping?
>
> Music: I tell the worker to piss off … [and if they don't] I might need to get physical [and push them out of my bedroom].

This example suggests that some people used physical actions when they did not like something and when workers did not respect their request. The implication of this type of complaining was that some people's harm experiences were compounded by workers not noticing, respecting or responding to their reactions, even when these reactions were in words.

Some people living in shared living arrangements also spoke about learning from their housemates how they could react more effectively. Some people said they had learnt they needed to speak louder so that workers would notice when they complained.

> Greatest Showman: Sometimes you do argue with them [workers] which is something that I hadn't done before moving in. [They need to see that it is] enough [for me] to get angry. Or annoyed. Seems to be working [workers are now responding].

The finding indicates that some people felt they needed to accentuate their reaction to workers when they did not like something the worker did. The inference is they learned to complain in heightened ways when workers did not notice they reacted to something they did not like.

Some people used physical actions that workers thought of as threatening or violent. Jane, a worker said, ‘One time Batman had a random shift change and didn’t like the person that turned up so then he chased them down the street (carrying a letterbox) to the cop shop.’

Silence

Some people reacted to conditions they did not like by becoming silent or withdrawing. Some workers described how they noticed changes in the way the person looked or the way they acted when they did not like something in the relationship. Joan, a worker, said, **‘**One of the habits Lion King does when they’re not happy, they don’t talk much. If you ask something to them they won’t respond.’ Some workers said some people also used silence when they did not trust their worker. Jane said,

> The support workers that Batman trusts more he will listen to and engage more with than the other ones. [With the workers that he doesn’t trust] he sort of just keeps to himself a bit more to keep himself safe, that’s his protection mode.

These findings suggest that some people reacted in visible, but subtle ways that were only noticed by workers who know them well. Through a lens of complaining, these subtle reactions were sometimes difficult for workers to notice as complaining. They also indicate that workers required a depth of knowledge about a person or receptivity to notice and translate people’s reactions as complaining.

Physical and verbal cues

Some people said they kept to themselves and sometimes they wanted their worker to notice and help them understand what they did not like. Rose said, **‘**Sometimes we sit down with a Kit Kat [and Sam (worker) asks questions]. Sam helps me unbundle my head. It gets my anxiety down.’ Some people needed support from workers to understand their experiences before they contemplated whether or how to complain.

People also complained using physical or verbal cues when they did not like something or wanted something to change. Some of these reactions were in response to circumstances changing without workers telling the person, or workers not respecting a person’s space or choices. Some workers described how they noticed these reactions, but did not interpret the reactions as complaining. For example, some workers described the way people complained as using physical cues to try to avoid something.

> Jane: Batman’s aware of his likes and dislikes. And if he doesn’t like something [or another worker] he will just deliberately get worked up as a distraction to avoid things.

This finding suggests that some people reacted in ways that were not easily accessible to others to be understood as a direct complaint about a specific problem, particularly to others that did not know the person well. The implication is that workers sometimes had difficulty noticing subtle complaining and had difficulty responding when the person's reaction did not directly relate to a problem the worker could notice.

Retreating

People commonly reacted to what they did not like by moving to spaces where they were alone. Specifically, many people said they went to their bedroom or a quiet place within or outside their home and sometimes expected workers to fix their problem without needing to ask.

> Researcher: What do you do if you don't like something?
>
> Greatest Showman: I normally go to another part of the house. Yep. My bedroom or outside. [And workers] they will actually go and tell my housemates not to do it anymore. Well, sometimes.

People said they retreated when they did not feel they could change something. Rose explained the following example, where the menu for the house was set for the week by the Thursday night worker. Rose said, 'Whoever [staff] is on Thursday night [sets the menu for the week, and if there is something that I don't like, I] might have something else … I might have tea down there [in my bedroom].' This example highlighted that the way people reacted to what they did not like was sometimes largely invisible to observers, including workers. Some workers did not easily notice that when people retreated it could be a reaction to what they did not like or could be seen as complaining or expressing dislike. Nevertheless, these retreating reactions were in response to dislike of some kind and were not easy to notice and did not involve words.

People also retreated when they could not resolve problems with their worker. People said they retreated even when what they did not like was not caused by the worker directly, but where discussions with workers did not result in resolving the problem. This type of reaction was illustrated in an example involving John Cena. John and his worker, Joe, both spoke about how John went to his room and stayed there until he was no longer bothered by something or had forgotten about the problem. John Cena said what he did was, 'Talk to Joe [support worker partner], or stay calm. And then [if that doesn't work] I would go to my room. Put my earphones and listen to music. And AFL [football].'

This finding suggests that some people retreated to quiet spaces when workers did not respond to their complaining or they resolved it in ways they did not like. Further, the example implies the strategy of retreating until they were no longer bothered or forgot about the problem suggests that the reaction was also a way to cope with unresolved problems.

Discussion

This research addressed a gap in the literature about complaining by people with cognitive disability. This article contributes to reconceptualising complaining and how people in relationships that are subject to paid social and contextual factors can be better supported to complain. The complaining by people with cognitive disability can be understood in the narrow sense (complaining in words) and broad sense of other reactions. A broad concept of complaining by people with cognitive disability is inclusive of the many expressions of and reactions to conditions in and about support relationships that a person does not like or wants to change – such as yelling, physical force, withdrawing and silence (Figure 1). This broad definition of complaining more fully acknowledges the agency of people with cognitive disability in their support relationships.

What is complaining

People complained often and in ways that were frequently not noticed by workers as complaining. The broad ways people complained connects scholarship about the communicative function of people's actions (Ramcharan et al. 2009) and the effect of adverse experiences (Dew et al. 2019a). Reconceptualising complaining through this connection uncovers the noticeable and less easily noticeable actions that people use to complain. The ways people complained, the function of their complaining and the interdependence of complaining are discussed here.

What ways do people complain

People showed that they complained with a wide variety and combination of actions and omissions, some of which were not easily noticeable as complaining. They rarely complained with words, instead they retreated, changed body language, used silence, or a combination of these. People also used verbal or physical actions to complain. Acknowledging these various ways people complained as complaining, particularly complaining by omission, is a useful conceptual contribution. Theories about complaining (Kowalski 1996) and empirical research about complaining by people with cognitive disability (Caspi 2024; Harding 2017; Wessel et al. 2012) usually focus on voiced complaining. Instead, the finding that most complaining was non-verbal, indirect or by omission is more closely connected to research that highlights the many ways people communicate. People communicate pain and distress in words and actions, or actions alone (Breau et al. 2000; Cooper 2009; McKenzie,

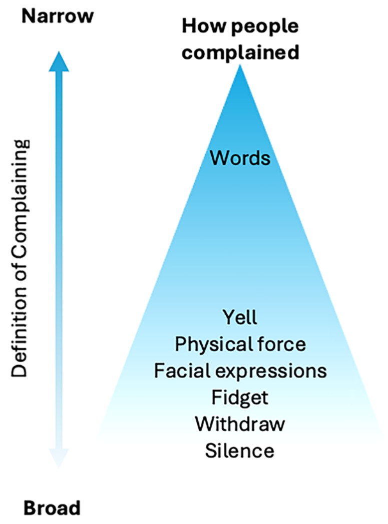

Figure 1. Rethinking complaining as actions and reactions to things people do not like in support relationships.

Smith, and Purcell 2013). Many people with cognitive disability rely on informal modes of communication, such as gestures and expressions (Forster and Iacono 2007). By broadening the understanding about the different ways that people complain to include actions that do not include words or only words, workers may be better equipped to notice and respond to people's reactions to something they do not like in the relationship.

Complaining as a communicative action

People complained to communicate when they did not like something in the relationship or when they wanted something to change. People complained about internal conditions and external conditions. Importantly, this conceptualisation of reactions as complaining does not mean that all acts by people were complaining. Instead, the broad notion of complaining may help workers to better notice reactions that may in fact be cases of complaining. The findings are consistent with research about the communicative function of people's behaviours and actions. This related research includes the responsive function of people's behaviours to internal or external causes (Cunningham, Macfarlane, and Brodaty 2019; Markwell 2016), but they are not described as complaining. A growing evidence base calls attention to the functions of people's behaviour as protest or resistance to environments or conditions they would like to change (Jorgensen, Nankervis, and Chan 2023; Macaulay 2018; Markwell 2016; Ramcharan et al. 2009). If workers interpreted people's actions or omissions as complaining, they might learn what the person does not like, how they communicate this and how the worker might respond.

People often relied on workers to notice, respond and help them resolve problems. Resolution of complaining was first dependent on the worker noticing and responding to what the person did not like. Understanding complaining by people with cognitive disability as an interdependent process reinforces the importance of quality support as interrelational. This contribution connects complaining to the relational context, where some people need help from workers to understand their needs, know they need assistance and know when or how to ask for it (Dew et al. 2019a), particularly when navigating complex service systems (Dew et al. 2019b; Williams and Porter 2017).

Implications for people with cognitive disability

Rethinking complaining as an act, whether intended or not, by someone in response to conditions they want to change situates their complaining act as a basic claim. This contribution makes clearer that workers and organisations have a responsibility for supporting the making of, responding to and resolving these claims. By doing so, people's complaining can more easily be seen as a claim for recognition within and outside the relationship. Recasting complaining by people as a claim can also reframe the negative associations about complaining. Rather than conceptualising complaining as an adverse act that should be avoided (Norlock 2018), the recast view of complaining frames it as a basic claim within a consumer and human rights orientated relationship.

Reconceptualising complaining also has implications for labelling around behavioural language by connecting the way people complained to the communicative function of people's reactions. Complaining in this way acknowledges that people frequently express themselves about what they want to change. The findings reinforce literature about people's challenging behaviours as responding to environments and conditions that they do not like (Jorgensen, Nankervis, and Chan 2023; Markwell 2016; Nankervis and Chan 2021).

The contribution about the importance of quality relationships and trust reinforces related research that highlights relational quality and trust as conditions that help people to feel safe and disclose when they feel unsafe (Robinson and Graham 2021) and to support their advocacy capabilities (Robinson and Graham 2019). This research extends current scholarship about quality relationships by highlighting their importance in supporting people to complain directly, within and outside the relationship. The findings suggest that supporting a person to complain is not just about knowing someone well but also involves approaching the relationship as one of mutual recognition.

Other important aspects which were considered in the broader study (Tomaszewski 2024) and which warrant further research include: how the duration and timing of complaining affected whether and how complaining was noticed or responded to by others; and whether and how people's complaining transitioned over time when they did not elicit a desired response.

Limitations

Although methods to support participation included mechanisms for people to participate in ways that did not privilege words alone, further research is necessary about the experiences of complaining by people who do not use words at all.

The data about complaining and misrecognitive experiences need to be read in the context of the broader research project. It would not have been ethical to ask participants directly about how and when they felt a lack of care, respect and valuing in their relationship, or how they complained when they did. A direct question would have risked negatively affecting their relationship or reliving trauma. Despite this, some people shared many and varied experiences of moments of misrecognition and what they did when they felt misrecognised in their relationship with their worker.

Conclusion

This study generated rich insights about how people with cognitive disability complain. The findings indicate that complaining needs to be understood both relationally and in a broader sense. The implications of the findings are important for the way paid support relationships are managed and the way institutions might develop and reflect on the accessibility of their feedback and complaint mechanisms. The findings emphasised that people often avoided speaking about things they did not like explicitly, particularly when asked directly.

The findings articulate complaining as relational, rather than as an individual act. These findings detail a level of relational experience of complaining that has not been described in paid support relationships before. This is important for extending knowledge and furthering a depth of understanding and vocabulary with which people's complaining can be understood.

Further research with people and their workers to better understand the interpersonal and institutional conditions that affect whether and how they complain is needed - particularly to better understand what helps and what makes it harder for people to complain and for workers to notice and respond when people complain.

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ORCID

Paul Tomaszewski http://orcid.org/0000-0003-4102-284X
Karen R. Fisher http://orcid.org/0000-0002-0828-6395
Sally Robinson http://orcid.org/0000-0002-5768-0065
Heikki Ikäheimo http://orcid.org/0000-0002-7755-5528

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