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Title 'I will never ever go back': Patients' written narratives of healthcare communication

Abstract

Introduction While communication with patients is essential to healthcare, education designed to develop patient-centred communication often ignores patients' voices. Patient stories may offer a means to explore patient experiences to inform patient-centred communication skills education design. Our questions were: RQ1 What are the features of patients' healthcare communication narratives? RQ2 What differences exist in patients' positively evaluated narratives compared to negatively evaluated narratives? RQ3 How do patients narrate emotion in their narratives?

Methods This interpretivist research was underpinned by social constructionism. We employed a narrative approach to design an online questionnaire that was advertised to patients in the community. Analysis of the stories that were generated involved analysis of *what* was written (i.e. framework analysis) and *how* it was written (i.e. attending to linguistic features).

Results Participants shared 180 written narratives about previous healthcare professional (HCP) communication interactions. Narratives commonly included female patients seeking help for musculoskeletal or psychological concerns, which most frequently occurred within the last 6 months with male general practitioners in community settings. Framework analysis revealed four key themes: 1) patient actions during consultations, 2) patient actions after, 3) lasting legacy and 4) interpersonal factors. Patients in positively evaluated narratives actively engaged during and after interactions, had ongoing positive relationships with HCPs and felt valued in these relationships. Patients in negatively

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evaluated narratives were either passive or active during interactions, but mostly failed to return to HCPs, feeling devalued in their interactions. Further analysis of linguistic features of select narratives revealed rich constructions of positive and negative emotions emphasising the lasting legacy of these interactions.

Discussion Patient narratives provide a detailed way of exploring patients' experiences, emotions and behaviours during and after consultations. Educational implications include emphasising the importance of valuing the patient, and of seeking and acting on patient feedback to calibrate HCPs' patient-centred communication practices.

Introduction

While 'good' communication between patients and healthcare professionals (HCPs) is pivotal to the safe and effective functioning of the healthcare system, we know that 'good' communication is not always enacted in healthcare practice. As educators, we try to address this issue through patient-centered communication skills teaching pre- and post-registration, at times with good effect.¹ However, despite educators espousing ideals of patient-centredness, real patients' voices are typically lacking in patient-centred communication skills education design.² Although active patient involvement is important to develop responsive healthcare curricula, it is still fairly uncommon in health professions education.^{3,4} This study therefore aims to privilege patients' written stories of healthcare communication, through narrative inquiry, to inform patient-centred communication skills education design.

We recognise that the term 'patient' is controversial (with some preferring 'client', 'consumer' and so on), however we use 'patient' in this paper because it is a well-recognised term and is synonymous with other terms that describe those in a therapeutic relationship with health care providers.^{3,4}

Patients' perspectives in healthcare and education

While the patient's voice is often lacking in the communication skills education literature⁵, patients are regularly canvassed for their perspectives on healthcare more broadly.⁶ Indeed, health service-led patient satisfaction surveys, for example, aim to improve the patient experience and form part of hospital accreditation or review.⁷ A typical component of this type of evaluation is the patient's perspectives on their interactions with HCPs and the communication skills of HCPs. Research into the patient's perspective has explored patients' preferences and ideas about good communication and the impact of communication on patient satisfaction.^{8,9} Although these perspectives contribute to our understanding of the patient's journey, it is unclear whether the results have been used to inform communication skills education or even whether questioning is detailed enough to influence improvements in patient care.⁷

The involvement of patients in health professions education is varied and ranges from full active partnership within pedagogical design, delivery and decision making, through to patients as teachers, simulated patients and paper-based patient scenarios.¹⁰ Specific to communication skills teaching,

patients are commonly involved as simulated patients in both teaching and assessment and workplace based learning with 'real' patient interaction is a key influence on skill development. Here, however, patients are often seen as the passive learning tool.⁴ While vignettes and case studies have been a longstanding component of health professions education, patients typically have little or no involvement in the development of such learning materials. Indeed, many of these case studies are generated by clinicians who, although well intended, may inadequately represent the patient's perspective in the storylines designed.

Healthcare narratives of personal experience

One way of incorporating the patient's perspective into health professions education design is through engaging with patient narratives.¹¹ More than just writing a story, personal narratives are described as constructions of lived reality that have entered the speaker's biography.¹² Narratives are an essential part of healthcare as they represent ways in which patients, and clinicians, can make sense of their healthcare experiences.^{13,14} Patient narratives have been promoted in health professions education as a medium through which healthcare students and clinicians can better engage with patient experiences and cultivate empathy.^{11,14} For example, Clandinin and colleagues describe narrative inquiry as a way of inquiring into experience that attends to the lived experience of the narrator, but also of the larger context within which that individual exists.¹⁵ As such, narratives may provide a rich description of the patient experience that alternative approaches to accessing patient perspectives may not.

Qualitative approaches to the analysis of narratives can follow two paths: analysis of the *what* and the *how*. Influential work by Labov¹⁶ proposes the structure of a typical narrative, which provides a framework for understanding *what* happened in a narrated experience. This framework includes the abstract, which is described as the initial section of a story providing the gist of what happened. This is typically, but not always, followed by the orientation, which is the description of the temporal, situational and spatial information and then complicating actions, which effectively describes what happened.¹⁶ Narratives also include a key social act or event. This is the clause, or section of the narrative, that allows the narrator to 'hold the floor'.¹⁶ Finally, narratives can be concluded with a resolution, and then sometimes a coda, which is the clause that returns the narrative back into the present.¹⁶

Through analysing *how* one talks about an experience, researchers can examine how an individual constructs the world around them.¹⁷⁻¹⁹ Scholars engage with a variety of analytical lenses in order to analyse the rhetorical use of narratives.^{17,20} Linguistic and symbolic tools (e.g. emotional talk and grammatical emphasis) are means used by narrators to construct their emotions in written narratives of personal experience.²¹ Through these discursive means, narratives reveal information about the narrator's feelings or emotions, which often comes in the form of evaluative clauses (i.e. positive or negative statements). Narratives of personal experience can evoke strong emotions and prompt the audience (i.e. learner, reader, researcher, policy maker) to reflect on similar experiences or episodes in

their own personal experiences and to empathise with the narrator.^{22,23} Indeed, emotion is inextricably linked to narrative and the exploration of emotion related to personal experience is particularly relevant in healthcare.^{24,25} Links have also been identified between emotions, patient satisfaction and continuing patient involvement in healthcare.⁶

In health professions education research, narrative approaches have been used previously, but have most recently focused on healthcare students' experiences.²⁶⁻²⁹ Although illness narratives and other literary accounts of patients' experiences exist (for example, see¹¹) and eliciting a patient's unique story is a key aspect of patient-centred interviewing³⁰, there is a dearth of research collecting, analysing and interpreting patients' written narratives focusing on healthcare communication interactions. Indeed, in a recent review exploring patients' perspectives of physician communication, a range of analytical approaches were represented in the included studies (including content analysis and thematic analysis), however none have examined the *whats* and *hows* of narratives.³¹ Narrative inquiry, as a methodology for the study of experience and emotion, is well-suited to exploring the experiences of patients.

Research questions

We therefore investigated patients' narratives of healthcare interactions to explore *what* happened and also *how* patients constructed emotion in their narratives. Our aim was to explore these stories to explicitly inform patient-centred communication skills education design. The research questions addressed in this paper are:

RQ1 What are the features of patients' healthcare communication narratives?

RQ2 What differences exist in patients' positively evaluated narratives compared to negatively evaluated narratives?

RQ3 How do patients narrate emotion in their narratives?

Methods

Questionnaire Design

This interpretivist research was underpinned by social constructionism and aligns with the assumption that our knowledge of the world is constructed through interactions with others.¹⁹ As such, social interactions involving language and communication are seen as a key means by which individuals construct their knowledge, identities and experiences.¹⁹ Social constructionist research intends to explore these constructions, and in this study we chose narrative inquiry as our methodological research approach. Narrative inquiry approaches can include narrative interviewing to collect verbal narratives, or narrative questionnaires to collect written narratives. In this study, an anonymous online questionnaire was designed to collect written narratives as data. This questionnaire approach has been used successfully in other medical education research.^{28,29} An advantage of a written narrative questionnaire approach over interviewing is that this method enables an accessible and private way for

participants to volunteer their stories.³² Additionally, online questionnaires provide wide and large reach, streamlined data management and are relatively low cost.³²

The questionnaire began with a short demographic section. A series of open questions then asked patients about their healthcare-seeking behaviours (e.g. how regularly have you seen a healthcare professional?) and asked them to share what they thought was important in healthcare communication. Finally, patients were invited to share healthcare experiences as stories, focusing on their communication with HCPs. This section of the questionnaire was informed by the structure of narrative proposed by Labov¹⁶, and included the prompts described in Box 1.

Insert Box 1 about here

To generate a balanced sample, participants were invited to share more than one narrative and to share a second narrative describing a contrasting evaluation to the first narrative shared (i.e. if the first narrative was of a positive experience, they were asked then to provide a negative experience and vice versa). This form of narrative questioning, in an online questionnaire, has been used elsewhere to explore the narratives of healthcare students.^{26,33} However, to our knowledge, it has not been used to explore patients' narratives of healthcare communication interactions.

Sampling and participants

After ethics committee approval, sampling targeted volunteers over 18 years, who were or had previously been a patient, or a patient's primary carer. Participants were required to respond in English and could describe current or past events. Recruitment involved online advertising (i.e. emails, Facebook posts, Twitter, online mailing lists and university communications) and paper-based advertising (i.e. flyers in cafes, public spaces, community centres, universities, some small health services and local newspapers). Recruitment also relied on snowball sampling, as participants were asked to forward the online survey link to others who may be interested. A lottery (random prize draw) was used as a gesture of gratitude to the participants after completing the questionnaire.

Data analysis

Data analysis followed two complementary approaches. Initially, narrative data were analysed using framework analysis, which identified what the story was about. Here, categories were drawn from the data in a form of sense-making.^{20,34} Conversely, to think *with* stories, we analysed linguistic features of three full narratives. This approach identified how the stories were told and as such privileged the rhetoric use of narrative.^{20,35}

The stages of framework analysis included familiarization, identification of a thematic framework, indexing, charting and finally, mapping and interpretation.³⁴ In stage one, familiarisation, the research team (CD, CER, EM) familiarised themselves with a diverse sample of narratives and narrators to initiate the development of the coding framework. The primary researcher (CD) read and wrote detailed notes on a subset of 20 narratives. CER and EM reviewed half this subset (i.e. 10 narratives each) in the same

way. In stage 2, the team then met to discuss immediate findings, and at subsequent meetings the authors inductively generated a list of codes, from which a thematic coding framework was iteratively developed until agreement was reached. In stage three, the primary researcher indexed, or coded, all data against the coding framework using NVivo for Mac 11.4.1. Coding was checked in just over 10% of narratives by CER and EM. The entire coding framework is available from the primary author upon request, with a supplementary table providing a summary of main categories and themes (Table S1). Four key themes were identified and are reported in this paper. In stage four, these themes were charted (i.e. compared and contrasted) with respect to the evaluation of the narratives (i.e. positively or negatively evaluated) to specifically address RQ2. It was at this stage that associations and patterns were identified. In the final stages of analysis, the findings were mapped and interpreted with respect to the communication education literature.

To complement this framework analysis, we explored *how* these stories were narrated and to address RQ3. We specifically selected three narratives for analysis to illustrate positively and negatively evaluated events, and to explore how patients make sense of their emotions in these stories using linguistic and symbolic tools.²¹ By analysing *how* participants narrate their stories we hope to reveal additional insights that are hidden when analysing only *what* participants say.

Although analysis was primarily undertaken by one author (AA), each code and selected narrative was also iteratively reviewed by CC who is experienced in this approach. Finally, all analyses were reviewed by BB. All three researchers engaged with both analytical approaches from the beginning of each process and as such, were able to comment on individual interpretations and contrast these with others. Drawing on interpretivist principles, we appreciate that there will always be multiple interpretations of data, but these sequenced and purposeful discussion loops within the research team have enhanced confidence in the trustworthiness of the conclusions.

Results

One hundred and twenty-four people shared 180 narratives about healthcare communication interactions (56 participants shared two narratives each). Table 1 includes the demographic details of this sample. Participants were overwhelmingly female (n=104; 84%), Australian (n=104; 84%), and mainly spoke English at home (n=118, 95%). Those who shared narratives were most likely to be aged between 18-39 years (n=54; 44%) and had seen a HCP less than 5 times in the last 6 months (n=57; 46%). Most participants were from high socioeconomic statuses based on the employment information shared (n=85; 69%).

Insert Table 1 about here

Quotes from participants' narratives are presented with unique identifiers (e.g. Patient163) or pseudonyms (e.g. Connie), participant gender (e.g. F: Female, M: Male) and age bracket (e.g. between 18-39 years). Data presented throughout the results section may also include the following transcription

notations: ‘...’ where the quote is abridged for presentation or ‘[text]’ where the text has detail added or adjusted for clarity or anonymity. To stay *true* to the patient’s voice/writing, narratives were not edited for spelling or grammar.

What are the features of the healthcare communication narratives shared by patients?

In written narratives, participants described orienting features of their healthcare communication narratives. Orienting features are presented in Table 2 and expanded in the text with respect to *who*, *what*, *where* and *when* questions.

Who? Typical characters in these narratives were a female patient and a male GP. As participants were usually the patient protagonist, the participant characteristics summarised in Table 1 also indicate protagonist characteristics (see Table 2 for additional details).

What? Stories were typically about verbal face-to-face, dyadic consultations for a new, non-urgent healthcare problem. The actions of the HCP related to a spectrum of profession-specific clinical tasks related to the healthcare concern. Examples of clinical tasks included gathering a history, patient education, conducting a clinical examination (e.g. physical assessment), providing referrals for further investigations (e.g. imaging, blood work, specialist review), and providing prescriptions and completing procedures (e.g. including minor surgery, diagnostic imaging, manual therapy, immunisations, and intravenous cannulation). See Table 2 for additional details.

Where? Just over half of the narratives occurred in community primary care settings (see Table 2 for additional details).

When? Most narratives described events that occurred within the previous 6 months (see Table 2 for additional details).

Insert Table 2 about here

What differences exist in patients’ positively evaluated narratives compared to negatively evaluated narrative?

Narratives were coded as having a ‘positive’ (n=80) or ‘negative’ (n=97) evaluation. Three were coded as being of mixed evaluation (i.e. as both positive *and* negative) and were removed from this stage of the analysis. Evaluation was determined by participants’ descriptions of how they felt with respect to the communication interaction. If participants reported negative feelings towards the interaction they were coded as negative and vice versa. Participants commonly volunteered a negative story first (71, 63% of first narratives were negative), and a positive story second (39, 60% of second narratives were positive). While the features described in Table 2 were mostly similar across positive and negatively evaluated narratives, differences between these two types of narratives were seen with respect to the themes identified through the framework analysis.

In terms of the framework analysis, four main themes regarding *what* happened in the healthcare communication interactions were identified: Theme 1) Actions during consultations: referred to patient's behaviour *during* the healthcare interaction and the reasons they acted the way they did; Theme 2) Actions after consultations: this referred to what actions the patient reported taking *after* the healthcare interaction and the reasons why; Theme 3) Lasting legacy of consultations: this theme referred to the ongoing feelings patients reported after the interaction; and Theme 4) Interpersonal factors influencing consultations: referred to relational descriptors of the patient-HCP interaction. In the next section, we describe how these themes differed with respect to positively and negatively evaluated narratives. Table 3 provides illustrative quotations.

Positively evaluated narratives

In positively evaluated narratives, participants typically described themselves as being active during and after the interaction. During the consultation, patients reported that they actively communicated with the HCP and successfully asked questions (see Quote 1, Table 3). After positive interactions, participants typically followed HCP recommendations (see Quote 2, Table 3). Participants reported feeling satisfied with the HCP's care and felt safe, comfortable and valued within the interaction. When reflecting on the interaction, at the time of completing the survey, participants had ongoing positive thoughts about the HCP or team involved (see Quote 3, Table 3). Interpersonal factors that influenced positively evaluated narratives included trust (see Quote 4, Table 3), patients feeling valued by their HCPs, and a human connection between patients and HCPs.

Negatively evaluated narratives

In negatively evaluated narratives around half of the participants reported being passive during the encounter (n=47; 48%), while a similar number described being actively engaged (n=44; 45%). Those who reported *passivity during* the interaction, reported that they behaved passively because they felt patronized, disempowered or dissatisfied with their care. Some in this 'passive' group also believed that this was their only option: 'what else could they do?' (see Quote 5, Table 3). However, those who reported being *active during* the interaction in negatively evaluated narratives reported that they made their expectations or questions clear. These patients (or their carers, as seen in Quote 6, Table 3), reported that they became active because they were dissatisfied with their care, their expectations were not met or they felt ignored or devalued.

Interestingly, in most negatively evaluated narratives, participants reported taking action after the interaction, regardless of whether they were active or passive during. This typically involved intentionally not returning to the HCP in the story (see Quote 7, Table 3). Some participants sought care elsewhere, whereas others did not reveal whether they moved onto another HCP. Regarding how they felt when recounting these events during the questionnaire, these participants reported dissatisfaction. They also reported unresolved emotions such as feeling anxious, upset, confused, frustrated and angry (see Quote 8, Table 3). Interpersonal factors coded as influencing the negatively evaluated healthcare

interactions were generally the inverse of those identified in positively evaluated narratives. For example, lack of trust, feeling devalued (see Quote 9, Table 3), and insufficient safety within patient-HCP relationships were highlighted in negatively evaluated narratives.

Insert Table 3 about here

How do patients narrate emotion in their stories of communication interactions?

Participants used linguistic and symbolic tools such as positive emotional talk (e.g. 'I felt a sense of hopefulness'), negative emotional talk (e.g. 'to my mind I was becoming a nuisance'), adverbs (e.g. 'I felt *genuinely* cared for'), expletives (e.g. 'seriously fuck that guy'), capitalization (e.g. 'knew A LOT about it'), repetition (e.g. 'she *explained* what she was going to do, she *explained* why, she *explained* the science behind it) and exclamation marks (e.g. 'perhaps her manner had made previous patients avoid her!') to construct emotion in their narratives. In this section, we present an analysis of the evaluation and emotion expressed within three narratives. We present analyses of one positive narrative and two negative narratives (one where the participant was passive during and the other where the participant was active during the interaction). Narratives were selected to showcase the findings of our framework analysis and the differences between positively and negatively evaluated narratives.

Positively evaluated narrative: 'Even when things go wrong'

Evaluation: This first narrative is a positively evaluated one from Connie (pseudonym), a female social worker from metropolitan Australia, aged between 40-59 years. The narrated experience refers to Connie's interaction with a cardiologist after surgery. This interaction occurred within 6 months of Connie completing our survey. While the primary patient-HCP relationship discussed is between Connie and her cardiologist, she also mentions nurses involved in her care. This 412-word narrative reveals detail about the positive communication interaction including Connie's active role during the consultation. For example, Connie actively engages in question asking to achieve her goals (see line 17). Connie also reveals her action after the consultation, which involved returning for a second procedure (see Box 2).

Insert Box 2 about here

Emotion: Despite being evaluated as positive, Connie employs both positive and negative emotional talk in her narrative. In relation to her feelings towards her interaction with the cardiologist, Connie uses positive emotion talk (see line 12 and 37). She also uses terms such as 'responsive and helpful' (line 18), 'relieved' (line 30) and 'glad' (line 37). Connie also repeats the value-laden word 'trust' (line 30, 33) in her descriptions, which emphasises the confidence she has in her cardiologist's expertise. Connie employs negative emotion talk as well as adverbs of degree, like *extremely* and *very*, to highlight her negative feelings towards the cardiac procedure and her illness: '*extremely* frustrating and anxiety provoking' (line 26) and '*very* unpleasant' (line 31-32). Regarding how she feels now, Connie's positive

emotions relate to both the care and the communication she experienced. In the coda, Connie repeatedly uses the evaluative terms 'positive' and 'negative' to illustrate her point about the interconnection of healthcare interactions and outcomes (lines 41-46). Here, she uses a subordinate clause, 'even when things go wrong' (line 41-42), to indicate that positive outcomes can still occur despite unintended negative consequences (i.e. failure of her first cardiac surgery).

Negatively evaluated narrative (passive during): 'These were MY EYES'

Evaluation: The second narrative comes from Lesley (pseudonym), a primary school teacher from metropolitan Australia. Lesley did not share their gender or age in the questionnaire. The narrated experience took place 6-12 months ago within a tertiary care setting. The event involved an eye specialist reporting Lesley's test results. The interaction concluded with the specialist handing Lesley an information sheet and some eye drops with minimal engagement from Lesley. This narrative was coded as negative due to Lesley's negative emotional talk about the interaction and passive because Lesley appears to be passive within the communication interaction despite expressing dissatisfaction. Lesley however demonstrates some activity after the consultation in that they did not return after the interaction and reported a negative emotional legacy (see Box 3).

Insert Box 3 about here

Emotion: Lesley uses negative emotion talk to reveal *what* they felt, however other linguistic devices hint at the intensity of *how* Lesley felt about their experience. Indeed, Lesley uses capitalisation on four occasions to emphasise the emotional tone of the narrative (for example: 'he was SO ready for his next client', line 16). In this 246-word narrative, Lesley uses exclamation marks liberally as a means of emphasis. There are 17 exclamation marks in seven different places, and there are three occasions where Lesley includes three or more exclamation marks to highlight their emotional statements (e.g. 'I really wanted more information!!!!', line 21). The reader's attention is also drawn to the repetitive use of 'very', which emphasizes Lesley's feelings towards the 'throughput of patients' and how pressured, and consequently undervalued they felt (see line 5). What is also revealed by this analysis is the emotional legacy that remains for Lesley. This narrative was written 6-12 months after their interaction and Lesley 'still feels' angry and helpless (line 27). In the coda (lines 31-32), Lesley uses the narrative to make a generalized statement about expectations of medical practitioners, communication practice and medical training. Again, using exclamation marks, Lesley emphasizes the importance of skilled communication in healthcare, 'Communication is the key!' (line 31), and pleas for other healthcare professionals to 'learn how to do this!!!!!!' (line 32).

Negatively evaluated narrative (active during): 'I will never ever go back'

Evaluation: The final narrative is a 468-word narrative from Julie (pseudonym), a female aged 40-59 years, who works in management in a healthcare service. Like the other narratives, she is from a metropolitan centre in Australia. Julie reports a negative interaction with a specialist to explore a treatment option. In contrast to the narrative from Lesley above, Julie constructs herself as an active

consumer during the interaction despite having minimal input. She leaves the interaction feeling particularly dissatisfied as she has had her opinion devalued and feels like she has wasted money. Like many negative narratives shared, Julie reports that she will not return to this specialist (see Box 4).

Inset Box 4 about here

Emotion: Julie uses negative emotional talk to evaluate her narrated experience. She describes the consult as 'one of the worst consults I have ever experienced' (line 21-22), and that she felt frustrated and angry (lines 32-33). She uses the adverbs 'ever' and 'very' to emphasise these emotions. Julie attempts to engage actively in the interaction, but repeatedly reports that she felt dismissed each time (e.g. line 8-9, line 16-17, line 34, line 41). In lines 22 and 40, Julie uses 'frankly' as an adverb to draw attention to the candid nature of her claims and her dissatisfaction with the doctor's attitude and service. Regarding her feelings at the time of recounting the experience, Julie uses repetitive emotional talk to describe that she was 'still appalled by it' (line 38), and 'it was an appalling consult' (line 39). Julie reported that while she complained to the receptionist, she did not complain directly to the doctor despite her negative emotion talk. Three times she voiced regret for not saying something (e.g. line 21, 32, 39), indicating the lasting emotional legacy of the interaction that occurred 5 years prior.

Discussion

Key findings and comparisons with existing literature

This study analysed 180 Australian patient narratives of healthcare communication. We found that, typically, these written narrated experiences were about a dyadic interaction between female patients and male GPs, about musculoskeletal or psychological concerns. The narrated experiences mainly occurred in primary care settings within the last 6 months. Four themes were identified that described what patients did during and after the interaction, how they felt after the interaction and the interpersonal features of the interactions. In positively evaluated narratives, patients were active before and after the interactions and expressed positive emotions that resulted in ongoing care. In negatively evaluated narratives, patients reported either passive or active roles during the encounters, but mostly did not return to their HCP after their experiences. Narratives contained positive and negative emotional talk, alongside other linguistic and symbolic tools employed to communicate emotion, which revealed deeper insights into the themes and their lasting legacy.

Our questionnaire study presented three typical narratives as demonstrated by Connie (positive and active before and after the interaction), Lesley (negative and passive during the interaction but active afterwards) and Julie (negative and active during and after the interaction). These types of narratives somewhat mirror the three communication states identified by van Bruinessen and colleagues in their qualitative study exploring the perspectives of patients with lymphoma.³⁶ With respect to provider-patient communication, these authors identified three states that patients moved through over time. The first state, *overwhelmed and passive*, aligned with findings in our 'negative and passive during'

narratives. Patients in this state contributed minimally to the interaction, felt distrust and fear. The second state, *pro-active and self-motivated*, mirrored somewhat our 'negative and active during' narratives. Patients in this state had a higher propensity for asking questions and gathering their own information but still felt dependent on the physician. The final state, *proficient and empowered*, was most like our 'positive and active' narratives. Patients in this third state were more skilled at engaging in interactions and experienced less difficulty in achieving their communication goals.³⁶ While the states described by van Bruinessen and colleagues are consecutive and relate to time since diagnosis, we did not gather such information in our narrative study, so cannot confirm whether our 'types' of narratives align with progression through states over time. However, our study builds on these findings and advances our understanding regarding what these 'types' may mean *after* the interaction once patients have left the consultation.

An overarching sentiment across the data seemed to be whether patients perceived they were valued, or not. 'Being valued' was characterised by patients feeling listened to, being given sufficient time by HCPs and when patient's input was acknowledged. These factors are not a surprise and have previously been said to form part of patients' descriptions of caring and preferences for doctor-patient communication.^{30, 37} It therefore makes sense that in positively evaluated narratives patients felt valued. Being valued appeared to effect both action *and* emotion. Indeed, patients who expressed that they felt valued were more likely to be engaged in the healthcare interaction during and after. The inverse was also seen in this study: when patients were not valued or when their input was limited, the interaction was negatively evaluated and patients did not engage with HCPs' recommendations after the interaction. Here, being valued and active engagement in the consultation are seen as being related, however not causal. The link between patient experience and adherence to recommendations, willingness to return, emotion and patient satisfaction has been found elsewhere.^{6, 38-40} However, these studies exploring patient experience and satisfaction have not employed a narrative approach that ties together different factors. Indeed, unlike the novel approach in the current study, these investigations are unable to tell a detailed story of the patient experience during and after the consultation. Even if narrative approaches have been used, for example Mishler's¹³ work, previous studies have not used a questionnaire with Labovian prompts thus gaining comprehensive and rich narratives. Furthermore, few of these investigations have illustrated the relationship between satisfaction and patients' narrative construction of emotion as we have done here.

Through analysis of patient narratives, our study has identified the longevity of negative emotions. Patients seemed to hold onto these feelings after months and years had passed. Similar findings have been reported in other narrative studies, with healthcare students, with regards to emotion and temporality.^{29, 41} In this current study, such negative emotions influenced future healthcare-seeking behaviour (i.e. patients typically did not return to specific HCPs). This loss of continuity of care has been associated with patient dissatisfaction, lack of trust, poor patient health outcomes and waste of resources (i.e. 'starting again' with a new HCP).⁴²⁻⁴⁴ Further to this, despite the emotion talk and

dissatisfaction expressed in negatively evaluated narratives, many patients in our study did not voice their concerns directly to the HCPs in question. The unintended consequences of such silence are that HCPs might never know the dissatisfaction felt by the patients they have seen. This absence of feedback may have implications for HCPs' understandings of their own communication practices. In this study, participants did voice their concerns by completing this survey, which could be seen as a form of resistance or them contesting their experience.^{13, 45} However, this is still not a form of feedback to the individual HCP, which is a point of concern.

Methodological strengths and limitations

This study has both methodological strengths and limitations that should be taken into account when interpreting the findings. In terms of strengths, we gathered 180 volunteered stories about communication interactions from patients and by using the Labovian structure for our online questionnaire. This generated written narratives rich in detail in terms of actions and emotions during and after the events. This positions this study differently from other studies exploring patient narratives of personal experience. The diverse age of our sample is also advantageous. Furthermore, as far as the research team is aware, this is the first study exploring patients' stories of healthcare communication in this way. By collecting and interpreting patient narratives, we hope to have given voice to patients, voice which is currently lacking in the communication skills literature. The variety of both positive and negatively evaluated narratives in this sample is also a strength, as other studies using this approach have often focused on troublesome experiences only.^{28, 29} Finally, our team-based approach to data analysis brought rigour to the analysis.⁴⁶

However, there are also limitations to this study. The stories gathered were mainly from highly educated females, from metropolitan areas of Victoria in Australia. This homogeneity means that our findings are less transferable to males, and those from lower socioeconomic backgrounds or from rural areas. Additionally, these stories were overwhelming about GP interactions, meaning that our findings are less transferable to secondary or tertiary care (i.e. hospital) settings and to other HCPs. Finally, a limitation of inviting participants to share written narratives as opposed to verbal narratives meant that we were unable to clarify or probe for details, and that participants were able to craft their responses in a way that would not have been possible if asked for a verbal narrative on the spot.

Implications for educational practice and further research

Our findings provide useful and novel insights into patients' experiences of healthcare communication. Based on the findings from these patient stories, we recommend the following foci for patient-centred communication skills teaching. Firstly, narratives such as those presented in this paper could be used as authentic vignette prompts for teaching to provide greater detail to healthcare learners about patient experiences. Teaching and learning activities should highlight aspects of patient-centred communication, such as valuing patients in healthcare interactions and recognising emotion. There is an increasing shift to patient-centred communication teaching as evidenced by the growing body of

research evaluating approaches, and the establishment of patient-centred communication resources through bodies such as the International Association of Communication in Health Care.^{47,48} These narratives may work well within other available resources and patient-centred communication teaching frameworks.^{1,48}

Secondly, communication skills teaching could focus on developing skills in seeking patient feedback as one aspect of monitoring the patient-HCP relationship. Learners, for example, could be taught to seek and act on patient feedback (within and after sessions) in a professional and appropriate way to calibrate their interpretations of the patient experience and their own patient-centred communication practices.

Future research could engage participants from demographic groups under-represented in this study, and target experiences in settings outside of primary care to broaden the transferability of these study findings. Additionally, research exploring narratives of the same communication interaction from the viewpoints of both HCP *and* patient, or alternative data collection approaches such as narrative interviews, may provide additional perspectives through which to explore actions and construction of emotion. The two-way dialogue afforded by interviews may also provide additional clarification and less edited versions of participants' responses. Furthermore, narrative analysis privileging how narrators constructed their own and others' identities could provide greater detail of the patient-HCP relationship.

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Table 1 Participant demographics (n=124)

Gender	Age	Language spoken at home	SES based on job*	Cultural background
n (%)	n (%)	n (%)	n (%)	n (%)
Female: 104 (84%)	18-39: 54 (44%)	English: 118 (95%)	High: 85 (69%)	Australian: 104 (84%)
Male: 19 (15%)	40-59: 38 (31%)	Other (inclusive of 2 Vietnamese, 2 Urdu, 1 Tamil, 1 German): 6 (5%)	Medium: 22 (18%)	Asian: 10 (8%)
Not specified: 1 (1%)	60-79: 31 (25%)		Student: 14 (11%)	European: 8 (6%)
	Unknown: 1 (1%)		Low: 1 (1%)	Other: 2 (2%)
			Unknown: 2 (2%)	

Notes: *SES=socio-economic status: High=68-100, Medium=34-67, Low=0-33 based on the AUSEI06⁵⁰

Table 2 Key features of narratives (n=180)

Who?	<ul style="list-style-type: none">▪ Narrators were the patient protagonist (154, 86%), or the primary carers (i.e. the patient was the narrator's elderly relative or child (19, 11%)▪ HCP gender was male (94, 52%), female (79, 44%) or unspecified (7, 4%)▪ HCPs were GPs (71, 39%), other doctors (48, 27%) or other HCPs, including nurses, physiotherapists, optometrists and dentists (44, 24%) or were unknown or unreported (17, 9%)
What?	<ul style="list-style-type: none">▪ Verbal face to face (169, 94%) or other (11, 6%)▪ Dyadic communication between patient (or main carer) and one HCP (127, 71%)▪ Initial consultations for a new problem (90, 50%) or follow-up contact with the HCP (39, 22%)▪ Non-urgent healthcare concerns (99, 55%), potentially serious or complex situations (44, 24%), or life-threatening incidents (19, 11%)▪ Musculoskeletal (29, 16%) or psychological concerns (19, 11%)
Where?	<ul style="list-style-type: none">▪ Community primary care settings (97, 54%), secondary (hospital) or tertiary (specialised) care (71, 39%), other (such as patient's home) and unreported (12, 7%)
When?	<ul style="list-style-type: none">▪ Within the last 6 months (59, 33%), 6-12 months ago (43, 24%), 1-5 years ago (45, 25%), more than 5 years ago (33, 18%)

Table 3 Illustrative quotes and summary of positively and negatively evaluated narratives

Themes	Positively evaluated narratives	Negatively evaluated narratives
Actions during	<p>Active: Communicated with HCP and asked questions</p> <p>Quote 1: <i>'I engaged with her more so than I usually did with my old specialist... I believe this happened because the doctor approached me as any other person would... In my opinion, I felt more relaxed and so it was easier to share. This made me feel very happy to visit my specialist and discuss my health, whereas usually I was particularly quiet and not always forthcoming with my thoughts' (Patient56, M, 18-39)</i></p>	<p>Passive: Minimal engagement with HCP</p> <p>Quote 5 [passive]: <i>'[I] lay quietly - feeling anxious and looking forward to the procedure to finish. [I] didn't have much alternative. [I felt] a huge lack of confidence, frightened, anxious, bothersome and demeaned' (Patient66, F, 60-79)</i></p> <p>Active: Assertively made expectations clear or asked questions</p> <p>Quote 6 [active]: <i>'I had to demand a medication review, geriatricians consult and had to make a real nuisance of myself because everyone assumed her [aunt] behaviour was due to dementia. She was a blind, frightened old lady!' (Patient110, F, 40-59)</i></p>
Action after	<p>Followed recommendations and returned for further care</p> <p>Quote 2: <i>'I followed her instructions with confidence in what I was doing and why I was doing it, and have since seen the exact results she predicted and have been very impressed... it was really [in] her best interest to look after me, not that I was simply an appointment in her day' (Patient130, F, 18-39)</i></p>	<p>Did not return to HCP and some sought care elsewhere</p> <p>Quote 7: <i>'Probably won't go back to the same dentist. Got the feeling like he was trying to get more business for himself rather than discuss with me whether together we agreed there was a problem first (i.e. putting his customer's needs first)' (Patient31, M, 18-39)</i></p>
Lasting legacy	<p>Ongoing positive thoughts about HCP or team</p> <p>Quote 3: <i>'I'm so grateful to this Doctor and he doesn't realise that those couple of visits changed my life for the better' (Patient33, F, 40-59)</i></p>	<p>Unresolved emotions, dissatisfaction with the specific HCP</p> <p>Quote 8: <i>'I still feel angry and upset when I tell the story. And I still feel very uncomfortable and unsafe when I have to go to see a doctor for any reason' (Patient29, F, 40-59)</i></p>

Interpersonal factors **Patient valued, trust, human connection**

Quote 4: *'He took the time to be sure we understood all we could - and he was empathetic about our [narrator and her daughter the patient] fears and concerns. His referral was quick and clear and so we knew we could trust him'* (Patient147, F, 40-59)

Patient devalued, lack of trust, lack of safety

Quote 9: *'It is awful when you know you are not okay and go to a professional that treats you like an interruption'* (Patient13, F, 40-59)

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