

QUALITATIVE PAPER

Discussing age-related functional decline in family medicine: a qualitative study that explores both patient and physician perceptions

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Abstract

Background: evaluating a patient's functional status and screening for geriatric syndromes by general practitioners (GPs) are increasingly encouraged. This study aimed to explore how older people and GPs define and perceive autonomy and functional decline, patients' propensity to discuss age-related issues and integration of such topics into routine medical consultations.

Methods: this qualitative study was conducted in Western Switzerland with older people followed in primary care practices and who participated in a trial assessing the effectiveness of a screening and management tool for geriatric syndromes to prevent functional decline. We interviewed 15 participants (patients ≥ 75 years old) and five GPs about their screening experience. We used semi-structured grids for data collection and an inductive thematic approach for data analysis.

Results: participants gave several definitions of autonomy, directly depending on their health status and functional limitations. Implementing various coping strategies, participants also expressed contrasted feelings related to functional decline such as fear, inability to accept and resilience. Functional decline was often perceived as normal ageing; participants were therefore not prompt at discussing age-related issues with their GP. However, screening was perceived positively by both participants and GPs, making addressing sensitive issues and detecting new problems possible.

Conclusions: a geriatric syndrome-screening intervention was well accepted by both patients and physicians. This type of initiative may be an opportunity to address various age-related issues and to inform patients of existing solutions.

Keywords: *autonomy, functional decline, ageing, screening, geriatric syndromes, primary care, qualitative, older people*

Introduction

Whilst being a positive outcome of increasing life expectancy, worldwide population ageing is a phenomenon that challenges health systems globally. Public health systems are responding to the changing demography by adapting services that contribute to helping older people live independently in their own homes as long as possible [1, 2]. Indeed, as developed in the socio-medical model of disablement by Verbrugge and Jette [3], an accumulation of chronic and acute conditions over time can limit individuals in their physical and mental activities and, depending on personal

and environmental factors, may lead to loss of independence and disablement. Until recently, health systems tried to address age-related functional decline through health assessments conducted during hospitalisation, rehabilitation after hospitalisation or within the context of home-based care [4]. These initiatives usually target individuals already impaired functionally or at high-risk of becoming so in the very near future. In order to intervene earlier in the disablement process, recent initiatives have aimed at screening for geriatric syndromes and functional decline in primary care settings, integrating assessment of functional status of patients in their usual environment [5–10]. General

Table 1. Screened geriatric syndromes

Items screened in the AGE tool
.....
Cognitive impairment
Mood disorder
Urinary incontinence
Gait instability
Vision impairment
Hearing impairment
Malnutrition
Osteoporosis

practitioners (GPs) are the main—and sometimes only—contact of the healthy older community-dwellers to the health system. Screening initiatives for geriatric syndromes further respond to the paradigm shift in medicine that evolved from a disease-centred to a patient-centred approach, by taking into account patients' health needs, goals and preferences [11, 12].

The Active Geriatric Evaluation (AGE) project was started in 2011 aiming to develop a screening and management tool for geriatric syndromes in family medicine (AGE tool) to prevent functional decline and improve quality of life in older patients in Western Switzerland [5, 13, 14]. The tool is currently being tested in a randomised controlled trial (AGE intervention trial) in which a usual care control arm is being compared with an intervention arm where GPs screen their patients during routine consultations for eight geriatric syndromes (see Table 1), with a targeted care plan for each syndrome detected. We hypothesised that the AGE tool could potentially be at odds with a patient-centred approach because of its standardised and syndrome-based nature and because it changes the routine consultation dynamics (screening initiated by GPs rather than on a patient's expressed demand). Based on this postulate, we integrated a qualitative study into the clinical trial to assess how the screening tool was perceived and accepted by patients and GPs. Our study aimed to explore the following: (i) how older people and GPs respectively define and perceive autonomy and functional decline, (ii) how older people discuss age-related issues with their GP and vice-versa and (iii) how the screening tool fits into the routine medical consultation.

Methods

Study design

This qualitative study was integrated into the AGE intervention trial (NCT 02618291, funded by the Swiss National Science Foundation). To explore the meaning of functional decline and autonomy in context, we conducted in-depth interviews with patients and GPs from the interventional arm. The ethics commission for research on human beings of the Canton of Vaud validated the study protocol (CER 2016–00422).

Setting and participants

The study took place in Western Switzerland and included patients aged ≥ 75 years. Throughout the article, patients are referred to as participants, and general practitioners as GPs. We recruited GPs during their training session on the screening tool (AGE trial), inviting them for an interview. We recruited patients of participating GPs (participants) using reasoned sampling for a fair distribution of socio-economic characteristics (age, sex, living place, social situation, education) and functional status. We contacted them by telephone and invited them to be interviewed face to face at home. We discontinued recruitment when sufficient insights into perceptions and acceptability of the screening tool were reached. All GPs and participants signed a written consent form.

Data collection

Data were collected between August 2017 and May 2018. Five GPs accepted to participate, and we conducted 15 in-depth interviews with participants in total. Interviews were conducted in French, using a semi-structured grid (in appendix), containing questions related to perceptions and definitions of autonomy, experiences of functional decline and how the screening topics were discussed during consultations. In public health literature on ageing, autonomy and independence in daily living activities are common terms that tend to overlap but differ. Autonomy refers to self-determination and ability to make choices (Atkinson (1991) and Macmillan (1986) cited in [15]) that cannot be dissociated from particular contexts or circumstances. Independence is defined as an individual level of physical functioning and ability to perform activities of daily living (ADL) unaided. Functional decline is understood as progressive limitation in abilities to perform ADL. During interviews, the term autonomy was mainly used to foster broader discussions, also because its common meaning in French encompasses concepts of both functional independence and self-determination. All interviews were audio-recorded, transcribed and anonymised.

Data analysis

We analysed data using thematic analysis within a realist paradigm, to explore experiences, meanings and the reality of participants [16]. Data analysis using maxQDA software (VERBI software GmbH, Germany) started during data collection. Open coding started after the first five interviews and was performed inductively by three researchers in parallel (O.V., J.S., Y.M.). Emerging codes were discussed and compared, and categories were redefined jointly by the research team and further explored over the following interviews. On completion of data collection, all interview transcripts were fully openly recoded by O.V. and discussed with J.S. Codes were assembled into categories and compared between participants, in light of their social and health contexts, to explore patterns and

Table 2. Sample characteristics

ID	Age	Sex	Living Setting	Education	Autonomy level	Living situation	GPs
1	86	Female	Semi-urban	Professional degree	Help for at least one activity	Alone	1
2	82	Female	Urban	High school	Help for at least one activity	Alone	1
3	76	Male	Rural	Tertiary degree	Fully autonomous	With partner	2
4	80	Male	Urban	Tertiary degree	Fully autonomous	With partner	5
5	86	Male	Urban	Tertiary degree	Help for at least one activity	With partner	5
6	81	Male	Urban	Tertiary degree	Fully autonomous	With partner	1
7	85	Male	Urban	Professional degree	Help for at least one activity	With partner	3
8	77	Male	Urban	Professional degree	Fully autonomous	With partner	1
9	84	Male	Rural	Secondary school	Fully autonomous	With partner	2
10	78	Female	Rural	Professional degree	Fully autonomous	With partner	4
11	86	Female	Urban	No school	Help for at least one activity	With partner	3
12	86	Female	Rural	Tertiary degree	Fully autonomous	With partner	2
13	88	Male	Rural	Tertiary degree	Help for at least one activity	Alone	6
14	80	Female	Urban	Professional degree	Fully autonomous	Alone	4
15	87	Female	Rural	High school	Help for at least one activity	Alone	6

trends. Categories were then assembled into themes. The inductive approach allowed identifying categories that had not been predefined and included in the original interview guide. Verbatim used in this article were translated from French into English by O.V., checked by an experienced translator and rechecked by authors to ensure meaning was maintained.

Results

Seven women and eight men aged 76–88 years were interviewed. Seven of the 15 participants lived in rural areas; six had obtained a tertiary degree, five a professional degree and four a high school education. Most of the participants lived with a partner; five were widowed or single, of which two had a family member who visited or called daily. Nine participants declared themselves fully independent in ADL, whilst others needed help for some daily tasks

(Table 2). Five GPs aged 37–59 were interviewed, mostly men (one woman), mainly from urban primary care practices (one rural).

Participants’ views on autonomy

Asked how they would define autonomy in their daily life, many participants described autonomy in terms of physical ability: ability to take care of one’s body (shower, get dressed, etc.) and being mobile. Participants living in rural areas often mentioned mobility linked to the capacity to drive their car. Only a few described autonomy in terms of cognitive ability, whilst several described autonomy as the ability to do things independently, without help from others. Indeed, definition of autonomy was largely contingent on functional status, ranging from a feeling of independence and freedom for those having no or few limitations—‘to do what I want’—to the ability to perform certain basic tasks independently, for those facing more limitations—‘to do what I can’. For

participants experiencing limitations, autonomy was primarily defined by the need to seek support and being dependent on others or not, as illustrated in this quote:

‘So far, though it’s difficult, I’m totally autonomous. I can even put on and take off my own support stockings, which isn’t easy. [...] I could count on my wife for help if needed, but for now I can cope.’ (ID 7).

Participants with greater limitations described their autonomy in terms of residual ability to do things, such as this woman:

‘[To me, autonomy means] that I can get up in the morning, I can get dressed, make my lunch and that I can even dust a little. Well, watch TV too [laughing] and do my crosswords. That’s it really- that I can still do things.’ (ID 1).

Overall, autonomy was expressed relative to others or to their previous autonomy, with participants often situating their level of autonomy compared with people around them of the same age and mainly to minimise their own limitations:

‘I see differences [in my abilities] yes, but I can’t complain compared to lots of other people of the same age I know.’ (ID 3).

Comparison with previous levels of autonomy was often related to ability to travel.

Attitudes towards functional decline

Participants described two types of phenomena hampering autonomy: acute events and ‘slowly setting-in’ issues. Facing an acute event, like a hip fracture, was often considered as transient loss of autonomy; during the interview, they described themselves as autonomous, referring to abilities before the accident. Non-accidental age-related issues were described as an insidiously slow process, a ‘slow deterioration’. Falls were considered with ambivalence, between an accident with temporary consequences and a slow setting-in change. They caused anxiety because of their often unexplained occurrence and potential recurrence, as expressed by this man:

‘I fell not so long ago, I still have the crutches there [showing the hallway]. I don’t understand how I managed to fall, because I felt like I was doing everything right but I still fell.’ (ID 8).

When functional limitations set in, participants use various coping strategies. Those experiencing gait instability explained how they avoided using stairs or going out of the house and how they arranged their living environment to make it safer. Others modified their social habits and goals to avoid risky situations, for example, walking less far to be sure to get back or avoiding taking public transport alone. These adaptations were expressed as ‘living more simply’ or doing things slower. Having a partner, a nearby family member or acquaintance was judged as facilitating autonomy in this respect. Adaptations could also have a different purpose, as explained by one man who, to avoid worrying his wife,

refrained from walking as he used to after an unexplained fall took him to hospital.

Participants experienced feelings of loss of autonomy ranging from fear, difficulty to accept and frustration, to a more resilient attitude. Whilst some expressed experiences and feelings around functional decline candidly, for others it was a sensitive issue, such as for this 78-year-old woman:

‘I think the main problem is accepting that you’re not the same. All of a sudden, you’re restricted, I don’t know if it’s the same for everyone, but for me that’s the hardest. (...) I used to be really enthusiastic. Not anymore. I used to be quite curious, but am less now. I used to travel a lot, but now I don’t want to. It’s sad, but that’s how it is. Quite awful.’ (ID 10).

Despite describing herself as a very independent, active person, this woman faced changes and limitations that she reported as having a very negative effect on her quality of life as they impacted valued activities such as gardening and pottery. This illustrates the nuance between autonomy defined by caregivers and its meaning for individuals.

Participants also expressed a fear of becoming dependent. Having to rely on help from others was perceived as rather negative, especially when it came to bodily care as expressed by this participant:

‘Not being able to wash, not being able to shave... I’d feel like I wasn’t a man anymore, (...) I’d be a burden.’ (ID 8).

Some participants expressed their greatest fear was to have to leave their home for a nursing home. One man said he would rather ‘jump off a bridge’ than live in an institution. Another explained that her main goal was to continue living at home:

‘Every day that goes by I say to myself: ‘It’s a day less in a home!’ (ID 15).

Others, often those still very active, living alone or getting minimal help, considered present or future changes with greater serenity. This participant reported experiencing functional decline with resignation, being grateful about his remaining abilities: ‘Well, it’s coming very slowly, so you can’t be disappointed’ (ID 13). Some also accepted the idea of needing support as a form of adjustment, like this woman: ‘Well, I helped before, they should help me now’. (ID 14).

Altogether, many participants talked about ageing as a normal process. Loss of strength, mobility and memory were often reported as ‘normal with age’ and coped with. One participant said he would not talk about problems of normal ageing to his GP because ‘it’s normal to get old and weak’ (ID 3). To delay functional decline onset, participants mentioned eating healthily and practicing physical or cognitive activity rather than seeking support from their GP, as explained by this participant: ‘I keep moving. I think this is the best way for everything. (...) And it’s good for the head too huh? Because when the head goes well the rest goes too.’ (ID 14).

Distinctions between ‘normal’ and ‘abnormal’ issues actually determined whether participants discussed about or not with the GP, as we describe below.

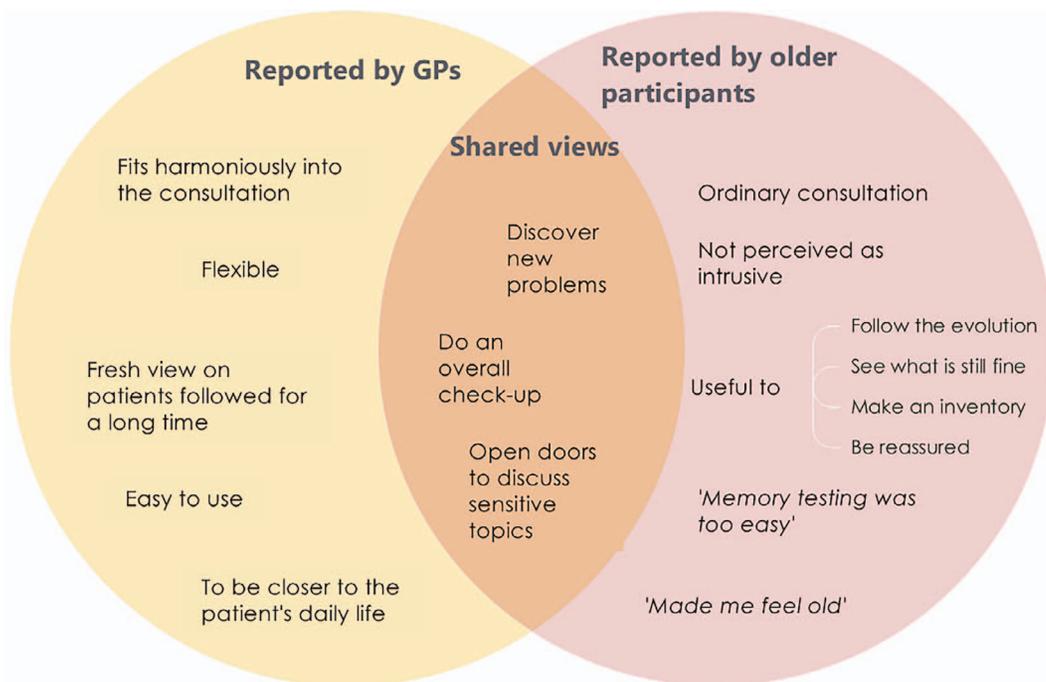


Figure 1. Items reported by older participants and GPs regarding screening of geriatric syndromes with the AGE tool.

Discussing age-related issues with the family physician

Regarding initiating a consultation, frail participants had regular visits with their GP for close follow-up, whilst participants in good health usually organised visits by themselves, either for periodic check-ups, when needing referral, or for acute health problems. Participants explained how they decided if a visit to the GP was necessary or not. Problems linked to ‘normal ageing’ were usually considered unnecessary, as illustrated by this participant:

‘I go [to my doctor], I tell him what’s wrong but ... Sometimes I don’t tell him everything [...] I think some of the things I have are because I’m not 20 anymore, so you know, there’s no need to ... make a fuss. [...] If my shoulder hurts now and then, it’s not every day, so I don’t want to go [to the doctor] every 5 minutes [laughs]. [...] It’s not really going to the doctor that bothers me, it’s thinking you went for nothing. I feel like I annoy him. Because I’m fine really.’ (ID 8).

Another reason for not talking about ‘normal ageing’ issues was the participants’ perception of absence of solutions. Memory loss in particular was an example of progressive impairment considered as ‘normal’ ageing, understood as a problem without medical solution and hence not requiring discussion with the GP:

‘I won’t mention it [losing my memory] to him. It is getting worse, but I never said it isn’t. Would I tell him about it? Well, I probably wouldn’t even think of it!’ (ID 3).

Most participants said they would discuss functional decline-related issues with their GP, but they all do not have the same inclination to do so. Some participants consider their GP a partner who they like to discuss and co-decide with. This man tells us:

‘I personally think a doctor’s role is to make you aware of something. He suggests things and I decide.’ (ID 6).

Many participants—usually with higher education levels—described their GP as someone providing advice about autonomy, but not as the one who could solve the problems. For others, however, the GP was a reference for everything related to their health, including autonomy, and they expected more than advice: the doctor is the one who ‘knows’. For this participant whose autonomy is threatened, the opportunity to talk about it is even essential:

‘It is very important to me. Because that’s what allows me to go on, despite ... all the difficulty. So, um, anything that can help my autonomy, I need to be able to talk to him about it.’ (ID 7).

Perceptions of active screening of ageing issues

Participants’ perceptions

When participants were asked what they remembered of the consultation that included the screening tool, it appeared that many of them had not really noticed it and perceived the consultation as usual. Some however noticed that several unusual questions were asked whilst the majority found it acceptable, even ‘normal’ because they expected their GP to ask questions about age-related issues.

Amongst the positive aspects reported by participants (Figure 1) was the fact that the screening moved beyond the regular introductory question ‘how are you?’

‘Usually, [the doctor] asks if everything is okay and we say yes. And that’s it. But perhaps with more specific questions, he’d be able to see that something’s not quite right.’ (ID 3).

Asking specific questions was seen as a way to ‘dig deeper’, an opportunity to talk about age-related issues that might

have gone unnoticed in a regular consultation. One participant explained that as a result of the screening, he came to acknowledge his mood disorder with his GP:

‘In the screening, there are questions about sight, audition, memory, nutrition, osteoporosis, gait and mood . . . —He seemed to say that I am a bit depressed (. . .).—And what did you think about that?—I was surprised. And then I thought, well it’s possible. That’s all . . . (In a low voice).’ (ID3).

He further explained that he was not ‘a positive person by nature’ but stressed that he did not want to go into detail with his GP about it at this point.

Screening was experienced by some as a way to detect unapparent problems and of avoiding unanswered questions:

‘It seems to me the most important thing is that it reassures us. Isn’t it? If we’re reassured we can positively take part in some way to improve the situation.’ (ID 7).

Some participants highlighted that screening enhanced a discussion on the overall health situation, including the social environment and autonomy. However, one participant had the opposite view, expressing his GP knew very little about his ‘real’ living conditions, thus could only partially support him with age-related issues.

Finally, in terms of potential change in the consultation dynamics, as screening was initiated by the GP during a routine visit, participants reported no invasive or paternalist experience. Further, screening did not alter their idea of their health status or age-related representations. Overall, screening was often conducted in a ludic way, with most participants amused by the tests. Only one participant reported being surprised because the screening ‘made him feel old’ (ID 8).

GPs perceptions

GPs expressed that their role encompassed discussing autonomy and quality of life with their older patients, but that in practice, most visits were dedicated to acute events or known chronic issue management. Thus, they perceived the screening tool as an opportunity to set aside the known issues and assess the patients globally: ‘It’s useful to see with a fresh eye patients we’ve known for years and with whom we easily bypass things because we see them ageing progressively (. . .). So [the tool] is interesting because it provides warnings, allows us to reconsider the global evolution of the patient.’ (GP4).

All GPs perceived that the standardised tool brought them to discuss topics they seldom routinely explored (such as mood, incontinence, nutrition) and allowed picking-up on new items, such as the GP above who detected a mood disorder in a participant. It also seemed to bring broader discussion on in-context coping strategies. Views on when to use the screening tool differed amongst GPs: some thought they would use it if they identified signs of functional deterioration; others saw an advantage of systematic screening to detect such signs. These views were often driven by the financial aspect: some GPs noted that whilst accepted by the majority of patients, integration of the tool into routine

visits was not favoured by a fee-for-service scheme. Screening could be delegated to a (less costly) medical assistant, but as one GP expressed, the whole purpose would be lost: ‘Results are not very important. It’s rather the interaction it fosters.’ (GP2).

Discussion

This research provides an understanding of the experiences and perceptions of older people undergoing active screening of geriatric syndromes by their GP. In our sample of participants in fairly good health and living at home with or without care support, autonomy was described in terms of the ability to do things in daily living and ranged from ability to ‘freely do what I want’ to ‘do what I can’, depending on functional status. The term autonomy, used by participants, did not overlap exactly with definitions used in public health; it rarely included the ability to decide for oneself but encompassed the social environment. Lette *et al.* [17] made the same observation and hypothesised that ability to make decisions is not part of autonomy until cognitive problems occur. Similarly, Hofman *et al.* [18] explored the influence of age on health valuations, showing that the ‘oldest’-olds value functional independence the most and concluded that for clinical decision-making, health valuations by older people and practitioners should be reconciled. Other scholars revealed how attitudes and health in old age was contingent on multiple, cumulated life-course factors such as upbringing and living conditions, sense of internal control, self-esteem and personal traits [19, 20], which could only be partially included and addressed in routine medical consultations.

Our findings show that functional decline was rarely linked to an acute event but described as a slow and normal ageing process and as such did not require medical attention or response. Loss of strength, mobility and memory were experienced as ‘normal’ and coped with in daily life. Such findings were also reported in qualitative studies elsewhere: functional restrictions were often rationalised as normal and non-medical in old age [21, 22]. In that case, screening for geriatric syndromes appeared as an opportunity to discuss specific age-related issues and explore solutions in the medical sphere and beyond. This includes the age-related issues that are managed by patients, for instance, through deliberate restrictions to limit falls, which have the potential to decrease mobility and increase social isolation, thus ultimately autonomy [21, 23].

The AGE tool is a standardised instrument that appears very biomedical and non-personal. However, as our data suggest, the tool was mainly used as a support for voluntary broader discussion and exploration of health status in the specific context of older people. Through active screening, issues considered non-medical by older people could be better integrated, and the role of GPs could be re-specified to better address specific psychosocial needs beyond the biomedical sphere. Following the model of disablement of

Verbrugge and Jette [3], the AGE tool has great potential for early detection and intervention on one hand and providing improvements and support tailored more to patient's needs on the other because it envelopes two essential phases identified in the model: (i) evaluation of personal functional status and (ii) subsequent discussion on solutions and care plans that comprehend possible strategies to ensure older people's ADL such as 'activity accommodations, environmental modifications, psychological coping and external support'. This latter phase was not assessed within the timeframe of this study that focussed on the initial evaluation. How screening and management plans can best be inserted timely and financially into routine consultations warrants further investigation. Practices in Switzerland are moving towards less GP-centred to more multidisciplinary teams (including e.g., nurses, physiotherapists), opening up new opportunities for the care of older people and for the implementation of such screening tools.

Limitations

Our study sample included rather robust participants with a relatively high education level, and we did not explore acceptability and feasibility of screening in a more fragile or less educated population. Our sample was too small to explore the potential influence of social stratification differences, such as gender or education in reality and definitions of autonomy, as found elsewhere [24]. Participants were interviewed only a few days or weeks after the screening consultation and had not yet benefited from the management of any detected syndromes. We hypothesise that the consultation including the care plan is a further opportunity to discuss health status, coping strategies and arrangements in daily living in a shared decision. This needs to be further explored, in addition with the GPs' divergent inclination to use the tool systematically for all their older patients.

Conclusion

Whilst outcomes of the clinical trial will provide evidence of the health improvements of patients benefiting from the AGE screening, this study has established its general acceptability and suggestions for implementation in real settings. Although the AGE tool is a standardised intervention, it opens doors to discuss age-related issues that may go unnoticed or undisclosed because they are perceived as non-medical. It allows GPs and patients to discuss everyday reality regarding autonomy and functional decline beyond the medical sphere and ultimately to co-deciding on support measures such as home-based care to ensure safer and longer home-dwelling.

Key points

- Many aspects related to ageing are considered as 'normal' and non-medical by older people and therefore often not discussed in routine consultations with the GP.

- Screening for geriatric syndromes is perceived as an opportunity to identify and discuss issues considered age-related and more generally, to discuss the meaning of ageing for patients in context.
- Qualitative research embedded into an intervention trial brings understanding of potential benefits of geriatric assessment conducted in primary care.

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