



Communication of the diagnosis of HIV infection

The experiences and preferences of patients

Introduction

HIV infection is a medical problem that has focused attention on communication with patients, particularly on the moment of the delivery of the diagnosis - may represent bad news

The way in which a diagnosis of HIV infection is communicated may influence:

- how patients adapt to circumstances
- patient dissatisfaction and distress
- suicidal behavior
- treatment compliance
- outcomes in HIV care

Introduction

- Bad news has been associated with terminal illness, imminent or actual death and cancer
- Common in Oncology
 - large number of studies
 - focusing on patients' preferences regarding the communication of bad news
- There is little research about the experience of receiving an HIV infection diagnosis from the perspective of these patients.... even less regarding their preferences

Aims

- 1) How patients receive their HIV infection diagnosis (patients' experiences)
- 2) Patients' preferences in this situation
- 3) How patients' preferences compare with their experiences when receiving the diagnosis

Methods

- Eighty HIV infected outpatients of a central hospital in a major city in Portugal, who received an HIV-positive test result, responded to a self-report questionnaire on:
 - how they received the diagnosis of HIV
 - their preferences regarding aspects of this moment

Methods

Instrument

- Designed for this study, the questionnaire was based on a large review of the literature concerning patients' preferences on the communication of bad news

Experiences

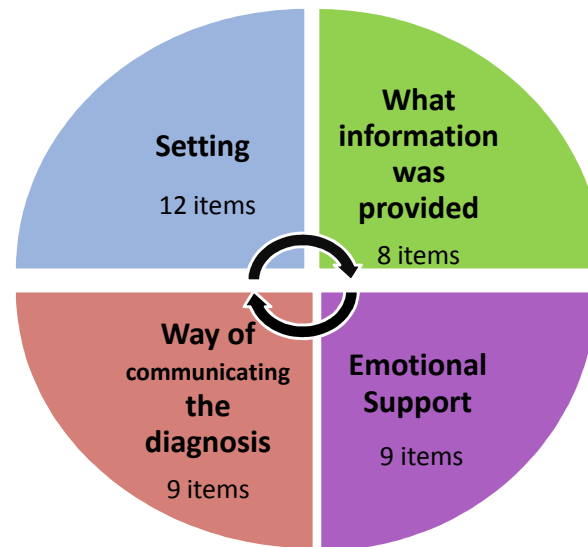
- 38 items
- Yes\No

Preferences

- 38 items
- Likert scale (1-5)

Socio-
demographic
and clinical
information

The questionnaire...



	Mean			SD	Range
Age (years)	42.3	8.27			24-61
Education (years)	8.35	4.01			4-19
Time since the HIV diagnosis (months)	91.9	77.9			1-276
	N	%			
Gender					
Male	51	63.8			
Female	29	36.3			
Nationality					
Portuguese	75	93.8			
Other	5	6.3			
Marital status					
Never married	32	40			
Married/living with partner	23	28.8			
Divorced	19	23.3			
Widowed	6	7.5			
Occupation					
Unemployed	33	41.3			
Employed	31	38.8			
Retired	16	20			
Sexual orientation					
Heterosexual	58	72.5			
Homosexual	16	20			
Bisexual	5	6.3			
HIV transmission					
Sexual	63	78.8			
IV drugs	17	21.3			
Diagnosis location					
Inpatient Care (Hospital)	19	23.8			
Outpatient Care (Hospital)	13	16.3			
Primary Care Centre	13	16.3			
Emergency room	11	13.8			
By letter	6	7.5			
Other	15	18.8			

Methods

Analysis

- Regression analyses and t -test were conducted in PASW-20

Results

Ways of receiving the diagnosis	Patients' preferences		Pref.-Exp. correspondence ¹	
	Mean	SD	Mean	SD
3. Give me information in a clear and understandable way	4.95	0.27	-0.05	0.28
10. Discuss the disease's implications in my everyday life	4.89	0.45	-0.14*	0.52
28. Ask me if I have any doubts or questions	4.89	4.23	0.21*	-0.32
25. Tell me in a private setting	4.89	0.55	0.57	-1.10
16. Give me information about the disease's progression	4.88	0.46	-0.09	0.31
26. Give the information in person (rather than over the phone)	4.85	0.68	-0.17	0.74
34. Schedule a follow-up appointment	4.85	0.42	0.32	-0.32
17. Check to see if I understood the information	4.84	0.49	0.18	-0.28
23. Give me support for my distress/fears	4.83	0.52	0.02	-0.15
15. Give me information about the treatment	4.81	0.55	-0.21*	0.60
13. Encourage me to ask questions	4.81	0.62	0.17	-0.42
36. Used the word "HIV/AIDS"	4.20	1.28	-0.61*	0.88

Discrepancies
(minus signal)



Highly valued
aspects did
not happen at
the time of the
delivery of the
diagnosis

... or vice-
versa

Results (Cont.)

Ways of receiving the diagnosis	Patients' preferences		Pref.-Exp. correspondence ¹	
	Mean	SD	Mean	SD
7. Immediately communicated all diagnosis details	3.64	1.68	0.35	-0.12
20. I'd like the senior doctor to give me the info. after discussing it with the team	3.38	1.69	0.91	-0.28
6. Give me the information with the help of exams/test/drawings	3.35	1.70	1.02*	0.03
30. I would like to be with my spouse/ partner	2.91	1.79	1.98**	-0.61
14. Give me extra written information	2.88	1.75	0.19	-0.08
19. Give me the information with other health professionals	2.86	1.80	2.23**	-0.67
31. I would like to be with a family member/friend	2.65	1.79	1.42	0.01

Agreement

In items that are not highly valued

* $p < 0.05$

** $p < 0.001$

¹Difference in mean preferences for each aspect between those who had the experience of that aspect and those who had not (t -test).

Results (Cont.)

Sociodemographic and clinical variables

- The location where patients received the diagnosis and their **nationality** influenced their preferences

			Beta	p
Patients receiving the diagnosis in outpatient care				
vs in the emergency room				
PREFER	➡	Information with the help of exams/ tests/drawings	-2.631	0.000
		Discussing the disease's implications in everyday life	-0.507	0.000
vs by letter				
PREFER	➡	Information without interruptions	-1.598	0.000
		Information about the treatment	-0.878	0.001
Portuguese nationality				
vs other nationalities				
PREFER	➡	Discussing the disease's implications in everyday life	-0.819	0.000

- Sociodemographic and clinical variables did not significantly influence patients' experiences

Discussion

- Patients' preferred...

The WAY information was communicated:

- In a clear way, asking for doubts and questions
- Not necessarily with the help of extra aids

The CONTEXT of communication:

- In privacy, in person
- Without the presence of family, friends, spouses or other health professionals

The CONTENT of the information:

- Disease's implications, progression and treatment
- Without immediately receiving all diagnosis details or hearing the word "HIV\AIDS"

Receiving EMOTIONAL SUPPORT:

- Having a follow-up appointment
- Support for fears\distress

Discussion (cont.)

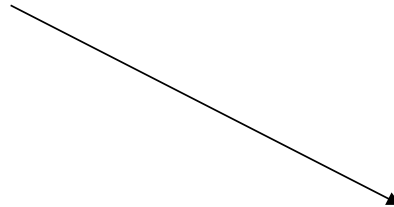
- Agreement between patients' preferences and their experiences occurred in several aspects. This agreement tended to occur for **aspects of low value for the patients**, notably...
 - Having spouses, family or friends present at the time of dx (as opposed with other conditions – e.g. cancer)
- On the contrary, there was **little** correspondence between patients' preferences and experiences for aspects patients **valued more...**
 - Disease's implications in everyday life and the treatment could be more explored
 - The word “HIV\AIDS” could be less used by doctors

Discussion (cont.)

- Only **nationality** and the **location** where patients received the dx affected their preferences



May reflect culture issues or
language barriers



Different needs associated with the
different contexts

- Socio-demographic and clinical variables did not influence patients' experiences.
 - These results were found in previous research

Limitations

- Small and convenience sample
- Retrospective
- Cross-sectional study

Conclusion

- Patients' preferences correspond to their experiences in several items which, however, are among patients' least valued aspects
- There was a tendency for discrepancies to exist between patients' experiences and preferences in patients' highly valued aspects
- This shows the importance of taking HIV infected patients' preferences into account when training clinicians in the delivery of this diagnosis

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